NURTURE NEVV JERSEY

STRATEGIC PLAN COMPANION DOCUMENT:

A Deeper Dive Into Data and Key Concepts

Making New Jersey
the safest and most
equitable place in the
nation to give birth
and raise a baby.



Nurture New Jersey Strategic Plan Companion Document: A Deeper Dive into Data and Key Concepts.

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Navigating the Strategic Plan

Nurture NJ is the First Lady of New Jersey's initiative, which aims to reduce maternal and infant mortality and morbidity and ensure equity in care and in outcomes for mothers and infants of all ethnic groups. The Nurture NJ Strategic Plan consists of three interrelated documents meant to advance Nurture NJ and achieve its strategic goals. These documents are:

- 1. The Nurture NJ Strategic Plan. This document contains all the Nurture NJ Strategic Plan Recommendations. While a summary of the recommendations is included in the Appendix, the recommendations are detailed on pages 41-72 of the Strategic Plan. The recommendations are preceded by summary background information on the challenges facing New Jersey with respect to maternal and infant health, racial inequities, and the key approaches to achieving the Nurture NJ goals. The recommendations are targeted to all public and private agencies and organizations, community-based organizations, business leaders and employers, funders, members of communities most affected by disparities in maternal and infant outcomes, and to all residents of New Jersey. With such a broad audience, there may be terms used in this and other documents that are unfamiliar. Readers should refer to the Glossary contained in the Nurture NJ Companion Document: A Deeper Dive for definitions.
- 2. The Nurture NJ Strategic Plan Companion Document: A Deeper Dive into Data and Key Concepts (The Companion Document). This Companion Document contains background papers that lay a foundation for understanding the context, impetus, and history of the need for the transformative recommendations of Nurture NJ. This document provides a thorough background on the data, key concepts, science, language, and references through which the recommendations can be understood in context. The Companion Document will be useful when applying for grants to support implementing the components of the Strategic Plan in communities. The Companion Document also contains a comprehensive plan for monitoring and evaluating an initiative like the Nurture NJ Strategic Plan. References to each paper in the Companion Document are included in the appendix.
- 3. **The Nurture NJ Year-One Playbook and Toolkit.** The Year-One Playbook and Toolkit includes suggested foundational activities that should take place in Year-One for each stakeholder group. To support these activities, it includes curated, newly developed or adapted implementation tools, resources, and guides to facilitate navigation of the pathways to actualize the Year-One activities. Stakeholders can make use of these tools to assist in translation of the Strategic Plan into action.

Even with the support of the Playbook and tools, there is no set recipe for how to implement the recommendations in this Plan. Each stakeholder, agency, or organization has its own strengths and limitations and these need to be factored into the development of agency-specific initiatives to accomplish this work. This work is necessarily transformative. Organizational and structural limitations should not be allowed to impede the work but need to be addressed with a transformative response. A transformative response entails modifying the organizational structures to accommodate innovation or partnering with other stakeholders who can fill the gaps to achieve outcomes. The existing structures and processes are perfectly designed to get the results they are currently getting, and this is what the Strategic Plan aims to change.

A Note on Language

The Nurture NJ Strategic Plan uses language conventions that are intended to be universal and inclusive. In this plan, we use the phrase "maternal and infant health" to refer to the health of pregnant individuals, which can include cis gender females, non-binary individuals, and transgender men, and their biological infants. We do not assume that all individuals that give birth to a child will care for that child, so we refer to caregivers, partners, and spouses, and the plan intends to address their well-being as well.

Methodology

Following First Lady Tammy Murphy's announcement of Nurture NJ in January of 2019, her office initiated a multi-pronged, multi-agency approach to improve maternal and infant health among New Jersey women and infants. This multi-sector formative stage laid the foundation for subsequent collaboration and is an important part of the methodology of the Strategic Plan's development. Highprofile events – including the annual Black Maternal and Infant Health Leadership Summit; the First Lady's Family Festivals; quarterly interdepartmental maternal and infant health meetings; and one-on-one meetings with key stakeholders and experts by the First Lady – raised consciousness about the challenges the State faces in maternal and infant health disparities, and generated commitment and productive action on the part of various stakeholders and communities.

In November 2019, a team of multidisciplinary experts was assembled to guide the development of a science-based, comprehensive, and actionable plan focused on equity and improved outcomes for all women and infants. The initial timeline was nine months from start to implementation of the Plan but was extended six months to accommodate disruptions caused by the COVID-19 pandemic. The strategic planning team attempted to model equity, community engagement, power-building and multisector partnership throughout the development process, as these are integral components of the Plan. The equity approach is informed by critical race theory, which includes identifying and addressing the effects of historical racism that is currently embedded in institutions and impacts life experiences for people of color.

The Strategic Planning process entailed:

- 1. An initial formative stage to develop interest, partnerships and common language;
- 2. Review of the scientific evidence on state-of-the-art methods for addressing inequities in maternal and infant health;
- 3. Development of an "Ecosystem Map" as a reference for stakeholders to understand the structural conditions necessary to achieve Nurture NJ's goals for healthy communities, healthy behaviors, respectful and effective clinical practice and equitable outcomes;
- 4. Integration of pre-existing work focused on developing a clinical blueprint for improved maternal health using quality improvement methods;
- 5. A statewide scan of existing state departments and agencies, organizations and stakeholders that directly or indirectly impact maternal and infant health;

- 6. Interviews with officials in eighteen state departments and agencies; seventy-five leading health providers, advocates, academic researchers, professional organizations, specialty task forces, funders; and a range of community-based and community-serving organizations;
- 7. Four in-person dialogue groups with resident women in South New Jersey and the coast (n=40), and four virtual dialogues with women in northern New Jersey (n= 30);
- 8. Development of action areas for improving maternal and infant health and eliminating disparities, aligned with identified state needs based on interviews and dialogues; and
- 9. Wide distribution of multiple Strategic Plan drafts to stakeholders across the state, with feedback provided verbally and in writing. Based on the comprehensive stakeholder participation in the planning process, the final Strategic Plan is considered to be a collaboratively developed product.



The Problems of Inequities,
Maternal Morbidity and
Mortality, and Infant
Morbidity and Mortality in
New Jersey



Section I.1. New Jersey Women Speak: New Jersey Isn't the Greatest Place to Give Birth Now

Diane L. Rowley, Pamela Brug, Terri Johnson, Bahby Banks, Pauline E. Brooks, & Jatesha "Jaye" Madden-Wilson

Nurture NJ aims to make New Jersey the safest place to give birth in the US. Eliminating health disparities, a prerequisite of becoming the safest place to give birth, will entail a transformative reenvisioning of what elements are essential to support the health and well-being of mothers and infants. Transformative changes start with responding to community voices and needs.

From October 2019 to August 2020, the Nurture NJ Strategic Planning Team held numerous community dialogues in southern, coastal, and northern New Jersey to better understand the experiences women have broadly with health relating to wellness care, pregnancy, and childbirth. The groups consisted mostly of women who had given birth in New Jersey, women who work as community health workers or doulas to women in New Jersey, advocates, and in some cases, health care providers.

The conversations held with Black and Brown women living in New Jersey revealed egregious problems with the healthcare system, many of which included racism. This paper summarizes Black and Latina women's experiences with maternity care in New Jersey and provides recommendations for fundamental changes that are urgently needed now.

In the Nurture NJ community dialogues, mothers talked about the beauty of motherhood, the joy of being able to create and raise children, and love them unconditionally. One said, "I can create life, I can sustain life, I can nurture ..." and another expressed, "I just love giving birth."

Their joy of having children contrasted with the negative experiences they had to endure to birth their children. Experiences with maternity care may affect pregnancy outcomes and there are many dimensions of maternity care performance, including whether women feel secure, feel treated with respect, feel adequately informed, and whether facilities are accessible and client-friendly.

I. Issues with prenatal care.

Women reported negative experiences with getting appointments. For example, one woman who relied on Medicaid said:

"It's hard to get an appointment. You have to physically go there to make an appointment and then the appointment, you know maybe two months later. It's discouraging when you are treated unfairly at your doctor's appointment and you have to wait so long."

Once in care, women expressed communications problems with providers. Women's concerns were ignored:

"My doctor didn't take any of my concerns seriously. I had a bleeding episode at nine weeks. They sent me home. They told me it was normal. I started bleeding again at 25 weeks. They sent me back home. They told me I was fine, that I was passing clots. They sent me home again. That last time my water broke and I had her."

Women reported unequal treatment based on the locations where they sought care, unequal treatment based on insurance status, and unequal treatment based on race/ethnicity. Prenatal care and labor and delivery vary tremendously by location. Care in low-income urban settings frequently was not quality care. The physical environment of the neighborhood where services were rendered made women uncomfortable, and for Black and Brown women, seem to parallel quality of the service:

"You can just close your eyes and ride down the street and feel the difference with the potholes and the area. I think there's a stigma working in the city as a healthcare provider that um...a lot of these facilities do have really poor care because of the stigma of living in the city...of being African American, of being Latina. You're stigmatized because of the health insurance..."

"There should definitely be more [for] the healthcare providers in the city, more training on cultural sensitivity and implicit bias. These doctors need to have better bedside manners."

"In some of these locations...I assume that there might be a higher volume of babies being born there so the level of care of things they are able to do....It's like a factory-in and out, in and out, in and out....Now that doesn't negate the fact that doctors should be providing a certain level of care, but I feel like it is a factory. They're on a conveyor belt. '

Women reported good care when they used facilities in suburban areas:

"When I had my second one it was in [a suburban location, name withheld] and when I went to the prenatal care the doctors were so nice. I asked them a whole bunch of questions. They knew exactly what to tell me. I got a tour of the hospital as well. Um...when he {the baby} came out everything was perfect with him, everything. Just the first one the experience was horrible and that's why I said I'm never having my baby at [name of city withheld] again. Because the doctor wasn't helping me. He just wasn't helping."

But women weren't always told about options regarding where to give birth. One woman said:

"You can definitely have Medicaid but it all depends on me learning [about options]. They didn't tell me that. I learnt it on my own. I Googled and looked it up. I didn't know that until I looked everything up myself and noticed that they had a different facility. So I said I no longer want to go here-I want to try this new one and it worked out great for me, But they don't share that with you."

And women shared their experiences with racism:

"Especially with a woman of color if you say something the wrong way then, oh something's wrong with you or you're crazy."

II. Labor and Delivery Care

Women shared their experiences at the hospital:

"They're just coming to have their children and they're treated poorly. I mean the whole idea of health care, they totally remove the care out of the profession. No mother should have the experience [of] what I felt and what dealt with."

"I got so many contradicting things from like the lactation consultant versus the nurses. And they were like walking in there saying like 'you need to give your baby formula. You need to give your baby [inaudible]. It was so stressful and no one was on the same page. I had no clue as of what to do with an infant, let alone that they had to eat every 2 and 1/2 hours...something that no one sat down and had a conversation with me. And um they started to label me as a troublemaker and which then became this thing where 'Oh, I don't want to talk to her. I don't like dealing with her.' And so it was just a horrible experience."

Providers ignored women's complaints of pain to the point of severe distress. One community health worker reported that a Latina woman had a C-section without anesthesia:

"I have a client and she had the baby in [facility name withheld] and they did the c-section without anesthesia. And she was screaming and was really, really bad. And she said 'I feel everything.' And they didn't pay attention to her."

Low-income women expressed that they are disrespected and devalued because doctors receive less money for treating women insured by Medicaid.

"I feel like sometimes the self-pay and type of insurance you have can make a difference because that's how some doctors get paid. And I feel like some people that are on Medicaid that live in the city of [name withheld]...they're often rushed and they don't hear them out. They are just quick to do the job that they've gotta do so they can get paid and move onto the next patient."

"If you go to the hospital and you got welfare or Medicaid, well you might just get welfare treatment."

III. Suggestions for Improvement

Women had strong ideas about how to improve their experiences.

"Birthing and pregnancy need to be celebrated like before...Moms need to be there for each other...another Mom or another person who has been through it should be there for that support...for the first year that that baby is born."

"If I had had a doula for all three pregnancies it would have been a world of difference...Coverage for doulas and healthcare practitioners that would not normally be covered...midwives."

Women want doctors and the health care system to be more accountable.

"I think there should be some sort of diagnosis code related to racial discrimination that links to illness and injury...that can be diagnoses like in insurance policies."

"I think that policies need to be changed... There are things that keep hospitals and agencies accountable in writing so that 'oh if we don't do this we lose money' then we'll start to see changes."

"I wish there was some certification or database where doctors can get certified ...for training, for feedback, like if we all could give feedback and say this person-we know they're legit, they care...We know you will have gold star treatment."

"We need to be empowered also. We talked about the doulas, the midwives and postpartum care and support groups. I think there needs to be an army of people in the city...empowered with resources, as well as money to support people."

"Every woman should have a [free] nurse to come home after you deliver because you are a first time Mom and you don't know what to think or what to do..."

Conclusion

In New Jersey there are many women—mostly women of color, low-income women, women who identify as LGBTQI, and women with disabilities—who live within a complex array of upstream and downstream contextual factors that compromise their opportunity to have a safe childbirth experience and outcome. In New Jersey, as in the US in general, so-called color-blind policies devalue, disempower, and differentially allocate societal resources and opportunities to groups based on their perceived value. At the core of what drives and maintains this hierarchy is structural racism that operates through multiple social conditions—housing, education, employment and wealth, credit, political participation, and the criminal justice system—linkages that are both historically rooted and culturally maintained, and interwoven into "a dynamic crisscrossing web of inequitable policies, procedures, practices and narratives that generally serve to maintain society's {inequitable} structures intact."^{2,3}

Recommendations

- 1. Accountability for the discriminatory care women receive during clinical encounters. Providers need to be directly informed when their actions have negative consequences. New person-centered quality performance measures need to be collected and used to evaluate healthcare. New Jersey needs to know what proportion of women of color experience disrespect, mistreatment or other negative experiences when seeking reproductive care. These performance measures should assess whether women are being listened to, spoken to in a way that is understandable, and whether women are adequately involved in decision-making about their care. Women must feel that they can honestly report their care experiences without retribution. (See Strategic Plan Recommendation 5.10)
- 2. Accountability for the quality of care women receive during clinical encounters. A monitoring system that scans the content of care is needed. As part of an intentional, participatory, transparent process, community leaders, representatives from midwifery, doula programs, and physicians, need to work with state government to continuously evaluate the provision of prenatal care. A first step would be to improve the conduct of the Perinatal Risk Assessment process conducted by the state of New Jersey and use it for all pregnant women. (See Strategic Plan Recommendation 7.6)
- 3. Accountability at the healthcare systems level. Institutional racism exists when systematic policies and practices within institutions disadvantage certain racial or ethnic groups. It occurs even when an organization does not intend to make distinctions based on race, but the combination of polices, practices, or procedures embedded in bureaucratic structure result in unequal outcomes for groups of people. All New Jersey health care systems need to undergo an anti-racism process and be evaluated for the changes they implement to reduce institutional racism. (See Strategic Plan Recommendations 1.1, 9.2)
- 4. Accountability for the social context where maternal deaths occur. Activities to reduce maternal and infant mortality and morbidity should be informed by place-based information about neighborhoods where maternal deaths and severe maternal morbidity are occurring in New Jersey. The number of maternal deaths in New Jersey is small relative to the total population, but by combining data with severe maternal morbidity, researchers can plot the neighborhoods where the most vulnerable women live. Mapping is valuable when merged with a wide variety of data resources to understand the ways in which neighborhood disadvantage affects health. It creates actionable information to improve health, food sources, type of housing, healthcare and social services. Community members can work with policymakers to explore residential factors associated with poor pregnancy outcomes in these neighborhoods and design interventions. (See Strategic Plan Recommendation 8.1)

Section I.2. Maternal Morbidity and Mortality in New Jersey

Jennifer Fearon, Mehnaz Mustafa, Erin Mayo, Genevieve Lalanne-Raymond, Abate Mammo, Alison Shippy, Amanda Medina-Forrester, Colette Lamothe-Galette, Lakota Kruse, Lisa Asare, Magda Schaler-Haynes, Marcela Maziarz, Marilyn Gorney-Daley, Mildred Mendez, Yannai Kranzler, & Debra Bingham

Summary:

New Jersey's maternal health outcomes and disparities are among the worst in the country, even though national estimates suggest that 66 percent of maternal deaths are preventable.

With the strategic vision of Nurture NJ to ensure that New Jersey becomes the safest place in the United States to give birth, analysis of current trends in maternal morbidity and mortality was conducted to identify trends and opportunities for reducing the high rates of adverse maternal outcomes. Both pregnancy-associated and pregnancy-related death rates have been on the increase in New Jersey. The pregnancy-associated death rate increased from 39.5 (2011-2013) to 45.9 (2016-2018) deaths per 100,000 live births. The pregnancy-related death ratio increased from 12.8 in 2011–2013 to 15.3 in 2014–2016. Black non-Hispanic women in New Jersey had approximately five times more pregnancy-related deaths than white non-Hispanic women. New Jersey's total severe maternal morbidity (SMM) rate was 192.2 per 10,000 delivery hospitalizations. These data demand urgent action to eliminate preventable pregnancy-associated deaths, pregnancy-related deaths, severe maternal morbidity, and to eliminate disparities.

Background:

In 2018, 96,480 mothers gave birth in New Jersey's 49 hospitals and three birthing centers. Among these, 32,765 delivery hospitalizations were NTSV (first-time mother=Nulliparous; fetus completed 37 weeks or more gestation=Term; one fetus=Singleton; head-first presentation at delivery=Vertex). NTSV is a measure used to identify a subset of pregnant women who have lower risk for requiring a surgical birth.

White non-Hispanic women accounted for 45 percent (n=42,913) of delivery hospitalizations, 30 percent (n=28,350) were Hispanic women, 13 percent (n=12,931) were Black non-Hispanic women, 11 percent (n=10,550) were Asian women, and 2 percent (n=1,696) were other or multi-race women.

Sixty five percent of delivery hospitalizations were covered through private insurance, 31 percent of deliveries were insured by Medicaid, 4 percent were covered through either self-pay or charity care.

Pregnancy-Associated and Pregnancy-Related Mortality in New Jersey. Pregnancy-associated deaths are those deaths that occur while a woman is pregnant or within one year of the termination of pregnancy, regardless of the cause. These deaths make up the universe of maternal mortality; within that universe are pregnancy-related deaths and pregnancy-associated, but not related deaths.

"It is eye opening to see the work that needs to be done and not a lot of people are doing it because we are not aware of what is going on in the maternal world. My cousin Ebony was very family oriented. She LOVED her children. At the time she had a 16-year-old son and a 2-year-old daughter. People loved her. She was soft, quiet, always smiling, very loving... She complained about headaches, she had a lot of swelling in her feet. So much so that she couldn't even walk...she did have to have an emergency c/section and then from here it was just downhill...one thing I will never forget her saying to me is how sad she was that they separated her from her baby...shortly after the blood transfusion her body rejected the blood transfusion. Shortly after, maybe a few hours she passed, and they tried to resuscitate her. We were there when it happened, and it just felt like unbelievable." Deyonna Phillips, NJ Community Doula (NJDOH, 2019, Voices of New Jersey's Maternal Health Crisis, NJ DOH Maternal Data Center, https://youtu.be/m1SapHNXUZc)¹

The New Jersey pregnancy-associated death ratio has been on the rise since 2011. The rate rose from 39.5 (2011-2013) to 45.9 per 100,000 live births (2016-2018) (refer to Figure 1).

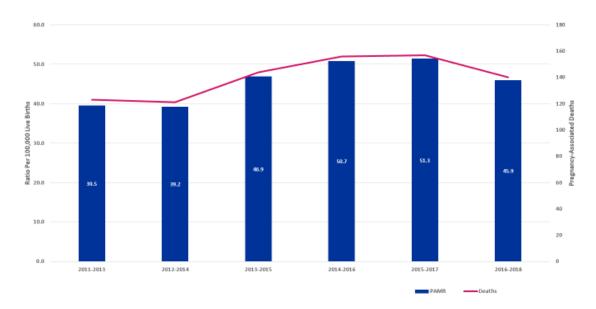


Figure 1: Distribution of Pregnancy-Associated Deaths, New Jersey (2011-2018)

Source: New Jersey Maternal Mortality Review Committee

The leading causes of pregnancy-associated deaths in 2017 were *substance use* 38 percent (n= 18), *cardiac/cardiomyopathy* 14 percent (n= 7), *infection/shock/sepsis* 14 percent (n= 7), *hemorrhage* 0 percent (n= 1), *homicides/suicides* 5 percent (n= 2), *trauma* 0 percent (n= 2), and *other* 29 percent (n= 14). The increase in pregnancy-associated deaths during 2015-2017 was primarily attributable to substance use (refer to Figure 2).

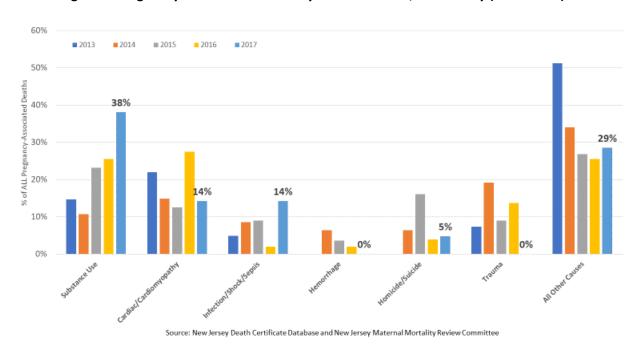


Figure 2: Pregnancy-Associated Deaths by Cause of Death, New Jersey (2013–2017)

Pregnancy-Related Death

Approximately one-third of pregnancy-associated deaths were designated by the NJMMC to be pregnancy-related deaths (refer to Figure 3). New Jersey's pregnancy-related death ratio per 100,000 live births has increased from 12.8 in 2011–2013 to 15.3 in 2014–2016 (refer to Figure 3).

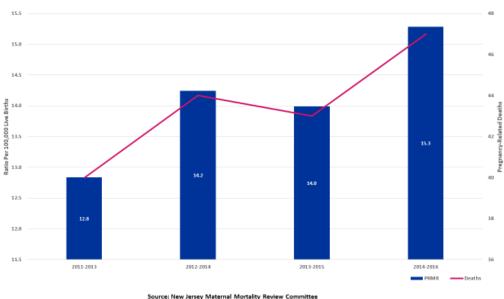


Figure 3: Pregnancy-Related Death Ratios, New Jersey (2011-2016)

Source: New Jersey Maternal Mortality Review Committee

The three top leading causes of pregnancy-related deaths in New Jersey during 2013-2015 accounted for 48-percent of the deaths. These included *hemorrhage/postpartum hemorrhage* 18.6 percent (n=8), *cardiac/cardiomyopathy* 16.3 percent (n=7), and *infection/sepsis* 14.0 percent (n=6). Other causes of death accounted for 51.2 percent of the pregnancy-related deaths and included amniotic fluid embolism, assault, drug related, embolism, HELLP syndrome (H=hemolysis, EL=elevated liver enzymes, LP=low platelets), Lupus, pseudoaneurysm, seizure, suicide, and other causes.

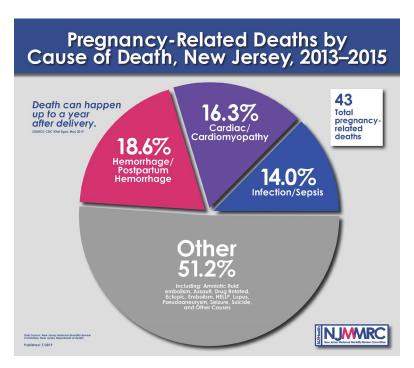


Figure 4: Pregnancy-Related Deaths by Cause of Death, New Jersey (2013-2015)

Timing of pregnancy-related deaths is summarized in Figure 5. Nationwide, approximately 33 percent of pregnancy-related deaths occur between one week to one year after delivery. However, 51.2 percent of pregnancy-related deaths in New Jersey occurred within only 42 days after delivery (2013-1015).

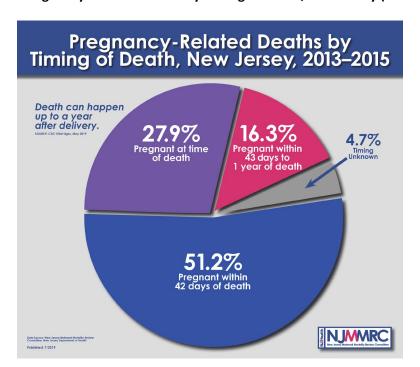


Figure 5: Pregnancy-Related Deaths by Timing of Death, New Jersey (2013-2017).

Severe Maternal Morbidity in New Jersey

"I wasn't just gaining weight, I was swelling...I didn't know what was wrong with me and I had to trust my doctor. He told me that I was pregnant. So that's what I went with. I think it was a Sunday night, and I was in bed and I woke my husband up and I was like, I think we need to go to the hospital because I was having so much trouble breathing. I got the impression that they felt that I was exaggerating or being dramatic. The doctor kept telling me you're fine. But they did blood work and took some tests and I remember the doctor's face when she came back to me and her words were exactly, Mrs. Thomas you're very, very sick. They said his heart rate was slowing and they had to do an emergency cesarean section. I wasn't allowed to see my son because I couldn't get up and go see him and they would not bring him to me...I had not heard of preeclampsia." Regine Thomas, NJ Real Estate Agent (NJDOH, 2019, Voices of New Jersey's Maternal Health Crisis, NJ DOH Maternal Data Center, https://youtu.be/m1SapHNXUZc)³

Maternal mortality is only the tip of the iceberg impacting maternal outcomes. For every woman who dies, many more women *nearly* die or suffer severe complications that alter their reproductive options. These morbidities can have negative lifelong effects on women's general health and well-being, and can include chronic pain, depression, and post-traumatic stress disorder. These events are referred to as severe maternal morbidity (SMM). SMM is defined as the unexpected outcomes of labor and delivery that result in significant short- or long-term consequences to a woman's health.⁴

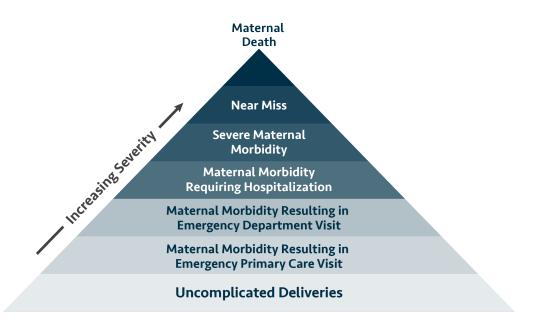


Figure 6: The Continuum of Maternal Birth Outcomes

In 2018, New Jersey's total severe maternal morbidity (SMM) rate was 192.2 per 10,000 delivery hospitalizations (including those with blood transfusions). Excluding blood transfusions, the 2018 New Jersey SMM rate was 66.9 per 10,000 delivery hospitalizations. This was an increase from the 2016 New Jersey total SMM of 181.7 (with blood transfusions) and 46.9 (excluding blood transfusions) per 10,000 delivery hospitalizations. In contrast, the 2014 (the most recent year these data are available) US rate of total severe maternal morbidity was 144.0 (with blood transfusions) and 35.0 (excluding blood transfusions) per 10,000 delivery hospitalizations.⁵

Figure 7: Severe Maternal Morbidity Rates with and without Blood Transfusions, New Jersey (2011–2018)



Data Sources: Healthcare Cost and Utilization Project (HCUP), AHRQ and NJ Hospital Discharge Data Collection System, Health Care Quality Assessment, Healthcare Quality and Informatics, NJ DOH



Leading Diagnoses of Severe Maternal Morbidity. The 20 leading diagnoses of SMM in New Jersey per 10,000 delivery hospitalizations in 2018 were disseminated intravascular coagulopathy (18.2), acute renal failure (12.2), sepsis (8.7), shock (8.2), adult respiratory distress syndrome (ARDS) (7.5) (refer to Figure 8).

In contrast, the leading SMM diagnoses in 2016 also included hysterectomies in the leading causes. Blood transfusions were excluded in the above breakdown because the percentage of SMM due to blood transfusions is always much greater than any other indicator of SMM.

Changes in practice have led to fewer hysterectomies and better recognition and treatment of preeclampsia. A shift in some indicators (sepsis and shock) may be due to changes in coding and better adherence to current guidelines in how to record clinical information.

Disseminated Intravascular Coagulation Acute Renal Failure Diagnoses Sepsis Shock Adult Respiratory Distress 2 4 6 8 10 12 14 16 18 20 Severe Maternal Morbidity Diagnosis per 10,000 Delivery Hospitalizations

Figure 8: Top 5 Severe Maternal Morbidity Diagnoses, New Jersey (2018)

Data Sources: Healthcare Cost and Utilization Project (HCUP), AHRQ and NJ Hospital Discharge Data Collection System, Health Care Quality Assessment, Healthcare Quality and Informatics, NJ DOH



NTSV Surgical Births in New Jersey. Hemorrhage and sepsis are leading diagnoses of SMM and leading causes of death in New Jersey and are more likely to occur after a surgical birth than after a vaginal birth. In 2018, the percentage of all births that were cesarean deliveries in New Jersey was 34.4 percent, and the percentage of NTSV surgical births in New Jersey in 2018 was 27.8-percent. This exceeds the national target (23.9 percent) established in Healthy People 2020. Based on these findings, New Jersey has seen a slight improvement in their cesarean delivery rates and NTSV cesarean rates since 2016 (35.7-percent and 30.3-percent, respectively).

In 2018, only 20 percent of New Jersey hospitals met the 2020 Healthy People target rate of 23.9 percent for NTSV cesarean rate.⁷

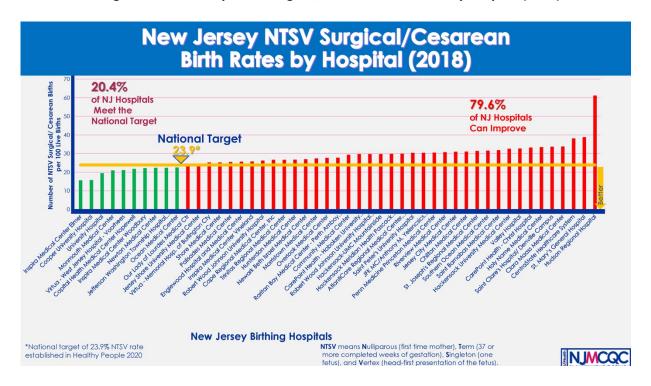


Figure 9: New Jersey NTSV Surgical/Cesarean Birth Rates by Hospital (2018)

Racial and Ethnic Disparities in Maternal Morbidity and in New Jersey. Disparities exist when one population group experiences a higher proportion of adverse outcomes in comparison to their population proportion. Disparities are often measured by comparing rates across race/ethnic groups to determine if any group has higher rates. Disparities in maternal outcomes are both unacceptable and preventable. Achieving health equity requires valuing everyone equally with focused efforts to address avoidable inequalities, historical and contemporary injustices, and disparate health care, recognizing the contribution of bias to poor health outcomes. Health equity requires efforts to ensure that all people have full access to opportunities based on their individual needs. These opportunities need to enable them to lead healthy lives. New Jersey's pregnancy-associated and pregnancy-related mortality and SMM data show many opportunities for improvement and the need to eliminate racist structures and biases.

Racial and Ethnic Disparities in Pregnancy-Associated Mortality Outcomes

The New Jersey 2018 pregnancy-associated death ratio for Black non-Hispanic women was 65.9 (n= 9), which was approximately twice as high as the ratio of pregnancy-associated deaths of white non-Hispanic women 38.0 (n=17) per 100,000 live births. Hispanic women's ratios of pregnancy-associated deaths were lower than white women's and Black non-Hispanic women's ratios.

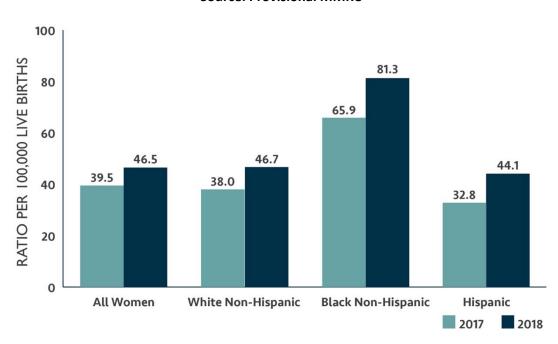


Figure 10: -Pregnancy-Associated Deaths by Race/Ethnicity, New Jersey, (2017-2018)

Source: Provisional MMRC

Racial and Ethnic Disparities in Pregnancy-Related Mortality Outcomes. Black non-Hispanic women (45.5 per 100,00 live births) in New Jersey during 2013–2015 had approximately five times more pregnancy-related deaths than white non-Hispanic women (8.6 per 100,000 live births). In contrast the CDC has reported that Black women in the US are three to four times more likely than white women to experience pregnancy-related mortality. Since New Jersey has among the worst outcomes in the US and the US has among the worst outcomes in the developed world, women giving birth in New Jersey are more likely to die than almost anywhere else in the developed world and Black non-Hispanic women fare the worst among New Jersey residents.

Analysis of 2014-2016 data shows that the pregnancy-related death ratio for Black non-Hispanic women (23.4) is approximately four times that of white non-Hispanic women (6.5) per 100,000 live births (refer to Figure 11). It should be noted that the disparity between pregnancy-related death ratios for Hispanic women and white non-Hispanic women increased from 2013-2015 (3.7 per 100,000 live births for Hispanic vs. 8.6 per 100,000 live births for white non-Hispanic) to 2014-2016 (13.3 per 100,000 live births for White non-Hispanic).

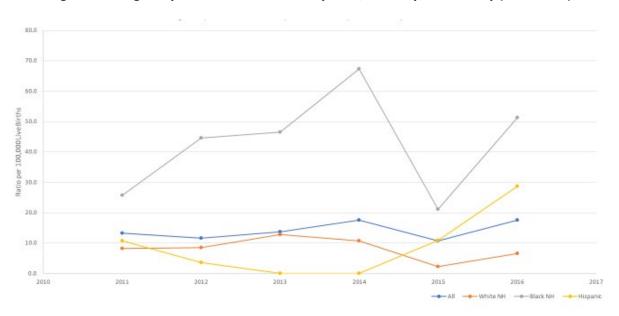


Figure 11: Pregnancy-Related Death Ratios by Race/Ethnicity, New Jersey (2011-2016)

Racial and Ethnic Disparities in Severe Maternal Morbidity Outcomes. New Jersey's 2018 rates of SMM per 10,000 hospitalizations among Black non-Hispanic women were nearly three times greater than those of white non-Hispanic women. Specifically, in 2018, Black non-Hispanic mothers had the highest rate of SMM with transfusion at a rate of 377 per 10,000 delivery hospitalizations, which is an increase from the 2016 rate of 312 per 10,000 delivery hospitalizations (refer to Figure 12). The 2018 rate for white non-Hispanic mothers was the lowest at 135 per 10,000 delivery hospitalizations. Overall New Jersey's rates of SMM are among the highest in the US and Black non-Hispanic women suffer the highest rates of SMM events.

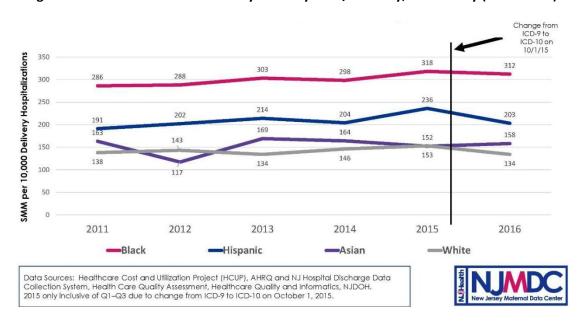


Figure 12: Severe Maternal Morbidity Rates by Race/Ethnicity, New Jersey (2011–2016)

SMM rates and disparities vary by indicator by year. In 2018, the rate of hysterectomy among Black non-Hispanic women was 10.3 per 10,000 delivery hospitalization for Black non-Hispanic women compared to 2.6 per 10,000 delivery hospitalization for white non-Hispanic women. There is over a three-fold difference in hysterectomy rates when comparing these rates by race and ethnicity.

In 2018, the leading causes of severe maternal morbidity among Black non-Hispanic women were: disseminated intravascular coagulation (30.8 per 10,000 delivery hospitalizations), acute renal failure (29.2 per 10,000 delivery hospitalizations), shock (21.3 per 10,000 delivery hospitalizations), eclampsia (15.0 per 10,000 delivery hospitalizations), and air and thrombotic embolism (11.1 per 10,000 delivery hospitalizations).

In 2018, Black women had a higher percentage of NTSV cesarean births than did white non-Hispanic women in approximately three-quarters of the hospitals (77 percent) where women give birth in New Jersey. However, the percentages for Asian women and Hispanic women were higher than for white non-Hispanic women in 51 percent and 53 percent of New Jersey hospitals, respectively.

Additional Sociodemographic Disparities in Severe Maternal Morbidity. In 2016, women in New Jersey who self-paid for their delivery hospitalization suffered the highest rate of severe maternal morbidity (234 per 10,000 delivery hospitalizations).

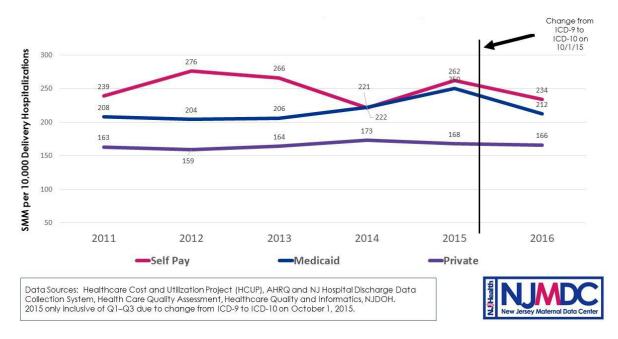


Figure 13 Severe Maternal Morbidity Rates by Insurance Type, New Jersey (2011–2016)

In 2015, women with the lowest incomes in New Jersey had the highest rate of severe maternal morbidity per 10,000 delivery hospitalizations at 278, compared to 161 among women in the highest income quartile.

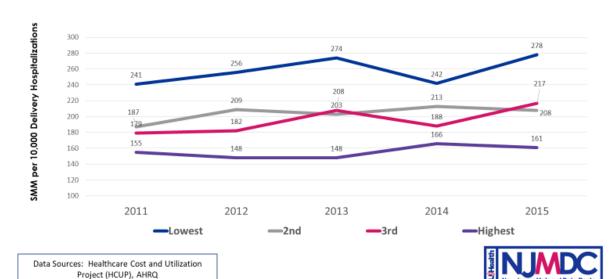


Figure 14: Severe Maternal Morbidity by Income Quartile, New Jersey (2011–2015)

Discussion

Summary of Key Findings. New Jersey has close to 100,000 births per year. Approximately 65-percent of pregnancies are covered by private insurance and 31 percent are covered by Medicaid. New Jersey's pregnancy-related death ratio has been increasing over the past decade and as of 2014-16 is 15.3 deaths per 100,000 deliveries. New Jersey ranks 43rd among all states on maternal mortality. The rate of Pregnancy Related Mortality (PRM) among Black women in New Jersey is four times the white rate, producing an unacceptable disparity in deaths. Leading causes of overall PRM are, in order: hemorrhage, cardiac related causes and infection/sepsis. In contrast to New Jersey, North Carolina has a similar number of annual births, but a higher percentage of births insured by Medicaid (54-percent), North Carolina has a lower PRM rate, ranks 17th in maternal deaths in the US, and has a smaller disparity ratio (1.6 compared to 4 in New Jersey). Yet, New Jersey ranks much higher than North Carolina on most economic indicators. This demonstrates that careful attention and action on addressing these preventable outcomes can result in improved rates. New Jersey has work to do.

However, there is room for optimism. The Centers for Disease Control and Prevention (CDC) finds that three in five pregnancy-related deaths are preventable. Specifically, evidence demonstrates that some leading causes of pregnancy-related deaths are *highly* preventable. For example, approximately 90 percent of hemorrhage-related deaths have been found to be preventable by state reviewers in California and among the findings of reviews from nine states. Review committees have identified hypertension-related and embolism-related deaths as some of the causes of death that are likely to be prevented. ^{10, 11}

Next Steps. Data-to-action is the goal and is an iterative process. The most effective data strategies include having accurate, timely, race/ethnicity, and location-specific quantitative data analyzed using an equity framework.¹² Access to data is key to strategic planning, developing specific goals, targets, and indicators, and tracking progress over time at the state and the birthing facility levels. It is also critical to make these data come alive by gathering and sharing women's birthing experiences. Sharing these data and collaboratively bringing meaning and designing solutions that support collective action are key next steps.

Ongoing surveillance activities must continue and their efforts must be expanded to include the annual public release of maternal data by race and ethnicity that can be utilized to guide actions. These data releases must be expanded to provide more timely, accurate, and granular data that include a portal where leaders in birthing facilities in New Jersey can access additional data on key SMM indicators (this portal is currently under development). Efforts that must continue and be expanded include the statewide maternal mortality data, case exemplars, and recommendations that are generated by the New Jersey Maternal Mortality Review Committee (NJMMRC), using a gold standard review process that is consistent with recommendations and guidance from the CDC. The New Jersey Maternal Data Center (NJMDC) includes the Report Card of Hospital Maternity Care, maternal mortality and morbidity data, breastfeeding by hospital, infographics, and a story bank. All data, whenever possible, are reported by race. The Healthcare Cost and Utilization Project (HCUP) provides trendlines for New Jersey's maternal morbidity rates. Other routine state data sources that must continue to gather and release contextual

information and process data include the Pregnancy Risk Assessment Monitoring System (PRAMS), the Perinatal Risk Assessment (PRA), and the State Health Assessment Database (NJSHAD).

While acting upon the lessons found in the data herein, New Jersey must remain responsive to emerging priorities, including New Jersey's COVID-19 crisis and opioid epidemic. At the time of writing, state epidemiologists and data experts are actively monitoring COVID-19 and stakeholders are actively devising and implementing evidence-based policy, practice, and programming. These committed collaborators are applying emerging data to ensure that New Jersey's women survive and thrive amidst the evolving COVID-19 crisis. Meanwhile, preliminary pregnancy-associated data demonstrates that a next focus for the New Jersey Maternal Mortality Review Committee will be assessing the causal relationship between substance use and maternal outcomes and identifying the most meaningful intervention mechanisms to avert preventable pregnancy-related deaths, such as the implementation of the Perinatal Risk Assessment for universal, non-punitive screening and for referrals to treatment for all substance users identified as well as the education of all perinatal clinicians, and training in harm reduction principles for pregnant or postpartum substance users.

Full implementation of the opportunities identified will require concerted and collaborative effort. Implementation by the New Jersey Maternal Care Quality Collaborative, the New Jersey Department of Health, and other key stakeholders requires a focus on improving data methods and accuracy, changing the culture and practice of maternal care, enhancing collaborations with a wide range of partners and organizations in New Jersey and nationally, identifying key stakeholders inside and outside of government, training and educating stakeholders, enhancing awareness and knowledge about the importance of high-quality, evidence-based, and appropriate maternal care, and ensuring equity in maternal outcomes. These data demonstrate that New Jersey's need to avert maternal mortality, to reduce maternal morbidity, and to promote health equity are ambitious and urgent. A full set of recommendations for how these data can be transformed into action are included in other sections of the Nurture NJ Strategic Plan. But, at a minimum, New Jersey needs to create a subscription portal for birthing facilities to access that includes key maternal healthcare indicators, publicly release annual updates to the maternal morbidity data via the maternal data center, and publicly release annual NJMMRC reports that outline the pregnancy-associated, pregnancy-related, and undetermined deaths ratios. Include in these reports leading causes of deaths, timing of deaths, opportunities for improving outcomes, and other data that will support efforts to eliminate preventable deaths and disparities.

The scale of New Jersey's maternal health crisis is massive. How quickly New Jersey reduces rates of severe maternal morbidity and mortality depends on how quickly all stakeholders work collaboratively across jurisdictions to implement the Strategic Plan recommendations.

Section I.3. Infant Mortality in New Jersey

Vijaya K. Hogan, Diane L. Rowley, & Jennifer F. Culhane

In the fall of 1996, the then Assistant Commissioner of the New Jersey Department of Health proposed the establishment of a Blue-Ribbon Panel to formally study the problem of Black infant mortality. The Panel identified five important factors about Black infant mortality:

- 1. The community lacks awareness that there were disparities in Black infant mortality and that high rates were a detriment to the Black community.
- 2. Psycho-social stressors, such as racism, are documented as factors contributing to Black infant mortality.
- 3. The existing arrangement of perinatal services does not adequately meet the needs of families at risk of Black infant mortality.
- 4. Programs dedicated to reducing Black infant mortality lack effective evaluation mechanisms.
- 5. There is more than one factor responsible for the high incidence of Black infant mortality.

The Panel developed recommendations to address these five findings. Healthy New Jersey 2000 set a goal to decrease Black infant mortality to 11.0 deaths per 1000 live births from the 1996 rate of 16.3 per 1000 live births by the Year 2000. In 2020, over a generation after the publication of these findings and recommendations, the Black infant mortality rate has just barely surpassed that year 2000 goal and the racial disparity in infant mortality persists.

Infant Morbidity and Mortality Trends in New Jersey.

Births. In 2018, New Jersey had 101,171 live births. The distribution of births by race/ethnicity are listed below (refer to Table 1 at the end of this section). The largest number of births are to white women, followed by Hispanic, Black, then Asian women.

Of these births, there are vast differences in sources of insurance covering pregnancy and birth. Insurance source was cited by women as a factor in defining the quality of care a woman received during pregnancy, with women reporting poorer treatment when insured by Medicaid and advantages to women with private insurance. Over the period 2013-2018, half of all births to Black women were insured by Medicaid, as were 45 percent of Hispanic births and 17 percent of white births. These differences in insurance coverage by population group can explain some of the disparities experienced in both care and outcomes.² In general, however, access to Medicaid is a positive influence on infant health, as states that have expanded Medicaid have seen declines in infant mortality rates.³

Eight cities accounted for 42 percent of Black births in New Jersey in 2017: Newark, Atlantic City, Camden, Trenton, Patterson, East Orange, Jersey City, and Irvington. The largest number of births to Black women occur in Newark (1930 births), East Orange (728 births), and Jersey City (763 births) (refer to Table 2 at the end of this section).

Infant mortality. New Jersey averages about 456 infant deaths per year. The overall infant mortality rate in New Jersey (2017) was 4.5 deaths per 1000 live births. The race/ethnicity specific trends in infant

mortality are in Table 2. There has been a slight increase in the last five years in the infant mortality rate for white and Hispanic babies, and a slight decrease in the Black infant mortality rate. Yet, the Black infant mortality rate is 3.5 times higher than that of white babies and the Hispanic rate is 1.4 times higher than the rate among white babies.

While the number of deaths is similar across racial/ethnic groups, Black babies suffer a disproportionate percent of all deaths. Under conditions of equity, the proportion of deaths should be at least commensurate with the proportion of births. This is not the case in New Jersey. Although Black infants make up 13.4 percent of all births, they account for 28 percent of all deaths—more than double the expected proportion. Hispanic births make up 26.9 percent of births and 29 percent of all deaths, and white infants make up 44.5 percent of births, but make up a lower proportion (26.5-percent) of all infant deaths.

The leading causes of infant death differ by race/ethnicity and the disparity remains across all causes (refer to Table 3 at the end of this section). For Black infants, the top three causes are Low Birthweight (LBW), congenital anomalies, and SIDS. For Hispanic infants, the top three causes are congenital anomalies, LBW, and maternal complications. For white infants, the three leading causes are congenital anomalies, SIDS, followed by LBW.

Further analysis of the deaths, using the Perinatal Periods of Risk Analysis (PPOR) (refer to Table 5), shows how infant deaths are distributed by the time period when the deaths could best be prevented. PPOR analysis segments the infant mortality rate into these periods of risk based on the baby's age at death and birthweight. The time periods are:

- Maternal Health/Prematurity—these deaths are best prevented by improving women's health before pregnancy
- Maternal Care— these deaths are best prevented via improved quality prenatal care (PNC)
- Newborn Care—these deaths are best prevented in hospital in the immediate postpartum period
- Infant Health—these deaths are best prevented in the postpartum period after hospital discharge.⁴

To interpret the PPOR, the overall infant mortality rate is segmented into different components to show how the overall rate (or number of deaths) is represented in each period of risk. The PPOR chart is like a pie chart that displays the proportion of the infant mortality that is attributable to either maternal health before pregnancy, maternal care during PNC and labor and delivery (L&D), newborn care immediately after birth, and postpartum infant care. The rates within each category add up to equal the total group-specific rate.

While the distribution of deaths differs for Black, Hispanic and white infants, the basic trend indicates that the majority of infant deaths in each group fall in the Maternal Health category indicating that the majority of deaths would have been best prevented through improving women's health before pregnancy.

There are extreme disparities in the Maternal Health category for Black and Hispanic infants compared to white infants. Twenty percent of Black infant deaths and 29 percent of Hispanic infant deaths fall into this category while only 6 percent of white deaths are attributed to this cause.

Table 6 at the end of this section shows the distribution of health conditions among women who gave birth 2013-2019 by race/ethnicity.

There is no consistent pattern across race/ethnic groups in reported pre-pregnancy conditions, with white women reporting higher rates of some conditions (diabetes, anxiety), and Black women others (obesity, asthma, smoking, physical abuse). In addition, it appears that Black women report being more likely to have had a regular check-up, an OB GYN check-up, or a family planning visit compared to white and Hispanic women. Despite these connections to pre-pregnancy care, Black women were more likely to get into prenatal care later than desired (refer to Table 5 at the end of this section). Overall, reported family planning usage was extremely low for all women.

Additionally, rates of infant deaths were higher for Black vs. white women even with a similar health condition. For example; among all infants born low birthweight whose mothers received PNC in the first trimester, Black infants had a mortality rate of 56.4 compared to 39.9 for Hispanic babies, and 23.4 for white babies. Co-morbidities, intergenerational and life course exposures likely play major roles in these differences and need to be further explored.

Breastfeeding. Breastfeeding is associated with significant reductions in overall infant mortality, neonatal mortality, and infection-related deaths. New Jersey set a goal of 50 percent of infants to be born in a Baby-Friendly facility. In 2015, only 18.9 percent of births occurred in these facilities. Since then, the number of Baby-Friendly facilities has increased to include 10 hospitals ⁵ (as of April 2020):

- Virtua Mt. Holly
- Jersey Shore University Medical Center
- South Ocean Medical Center
- Capital Health Medical Center
- Virtua Voorhees Hospital
- JFK Medical Center
- Our Lady of Lourdes Medical Center
- AtlantiCare Regional Medical Center
- Overlook Medical Center
- University Hospital Newark

These Baby-Friendly designated hospitals represent about 30 percent of the birthing facilities in New Jersey.

Infant deaths by Region (2005-2015). While the majority of infant births occur in Newark, East Orange and Jersey City, the highest rates of death occur in Atlantic County, Burlington and Camden (refer to Table 7 at the end of this section). The number of Black births, rate of infant death, and numbers insured by Medicaid all have implications for decisions regarding regional priorities in the state with respect to addressing Black infant mortality. However, while high infant deaths may show up in certain regions, the solutions are structural ones that affect the entire state and therefore the greatest impact will be seen through addressing the structural challenges across the state as a whole and within all regions.

Discussion and Conclusion. New Jersey has clear pockets of high infant mortality, high Black infant mortality, and large racial disparities; and these have persisted over time. The data point to a need for improved women's health and wellness as an important factor in addressing the disparities and reducing maternal and infant morbidity and mortality, and clearly point to a need to address racial disparities. A different approach is needed to eliminate racial/ethnic disparities and reduce overall infant mortality. It is also clear that these two actions—eliminating racial disparities and reducing overall rates—are mutually dependent. Nothing, however, will change unless New Jersey undertakes sustained action, using a different strategy, to address the high infant mortality and the racial inequities in infant mortality. Understanding has long preceded any ability to change it:

"While the reduction of New Jersey's Black infant mortality rate must be a statewide priority, it must also become a goal of public agencies, private enterprise and the general community. Black infant mortality is a multifaceted problem whose solution calls for many different initiatives; state government, industry, and the public must each contribute to the solution. Without united action, the problem of Black infant mortality will not go away."

The Blue Ribbon Panel Report on Black Infant Mortality Reduction

published September 1997.

What will be different now, almost a quarter of a century later, when the disparities have only gotten more severe? The Blue-Ribbon Panel Report was a thorough assessment of the contributors to disparities in infant mortality and its recommendations incorporated community insights as well as expert knowledge. One thing that has changed since its publication is that SARS COV-2 has alerted the public to the long history of racial inequities that cause Black populations in US cities to bear a disproportionate burden of illness people of color experience. However, some recommendations are as valuable today as they were when the report was written. They include:

- Inviting individuals and community organizations, civic groups, clergy associations, health care
 professional organizations, medical, nursing and social work associations, fraternities, corporations,
 educational institutions, hospitals, health centers, student groups, and consumers to form a publicprivate-community partnership;
- Fostering a health care environment sensitive to the specific emotional and physical needs of Black women;
- Ensuring that Black infant mortality programs both measure and report the impact of their interventions;
- Developing tools to appraise outcomes and cost effectiveness for state funded programs designed to decrease Black infant mortality; and
- Identifying tools to measure perceived racial discrimination for pregnant Black women.

The Panel should be congratulated on their insights; however, many of the recommendations were not activated to the level needed to create sustained change in inequitable rates. New programs may have been implemented, but they have not made a dent in the structural and contextual forces that constantly reproduce conditions that adversely impact women's and infant's health. New evidence-based interventions may have been instituted but they have not expanded their reach far enough to cover all those in need, nor have they consistently achieved the level of quality and respect that implementation requires to have impact on outcomes. Disparities in infant mortality have gotten progressively worse over time even though there is a stronger literature than existed in 1997 on what contributes to the elimination of these disparities. Nurture NJ creates an opportunity to restart a more structural and thus, sustained effort to reduce Black infant mortality and eliminate inequities in infant mortality. This time, the state will build toward a stronger statewide strategic mandate, implementation of new approaches based on the data, and development of new infrastructures to support the effort.

Table 1: Live Births by Race/Ethnicity, New Jersey, 2018

	Number	Percent of All Births
Black (NH)	13,537	13.4
Hispanic	27,212	26.9
White (NH)	45,006	44.5
Asian	11,705	11.8
Other	3,699	0.04
All Births	101,171	

Table 2: Black Infant Mortality Municipalities and Key Indicators, 2016

	New Jersey	Atlantic	Camden	Newark	Irvington	East Orange	Jersey City	Trenton	Paterson
Black NH Births (N)	13,639	191	442	1,930	675	728	763	559	502
Teen Births (%)	6.0	5.8	10.9	7.7	4.9	6.2	7.5	8.1	7.8
Medicaid (%)	53.1	85.4	82.3	65.7	60.9	58.3	63.2	64.6	67.7
Gestational Diabetes (%)	6.1	**	4.1	5.1	6.4	5.5	5.2	6.0	3.6
Gestational HBP (%)	7.2	7.9	8.1	7.1	6.7	6.5	5.6	8.4	6.4
Obesity (%)	66.4	71.7	66.9	65.1	65.0	64.9	60.7	69.6	66.1
Late/No PNC (%)	32.2	35.1	33.3	39.5	37.4	35.6	32.6	39.6	32.2
Smoked during pregnancy (%)	6.1	18.3	13.9	6.1	3.6	3.9	6.6	9.2	7.1
Preterm birth (%)	13.6	11.6	15.2	15.6	10.2	11.3	15.3	15.3	16.7
Low Birth Weight (%)	13.0	10.1	15.8	15.3	8.6	12.7	14.9	13.9	14.7
Exclusive BF at discharge (%)	24.8	19.7	29.6	17.7	18.0	24.8	16.5	33.1	14.9
Income below poverty line (%)	9.1	19.3	19.7	15.8	10.6	9.4	12.3	12.0	14.5
Median Household Income (\$)	47,299	20,981	25,426	30,429	38,987	39,205	41,427	32,615	32,075
Females (25+ years old) with no High school diploma (%)	12.6	27.3	23.5	16.7	15.8	13.3	13.1	17.4	17.5
Households led by women (%)	44.5	67.8	69.9	57.2	46.6	48.8	50.6	56.0	57.3

Source: New Jersey Birth Certificate Database, New Jersey Department of Health and

American Community Survey 2012-2016, US Census Bureau

Table 3: Infant Mortality Rates (deaths per 1000 Live Births), New Jersey, 2013-2018, by Race/Ethnicity

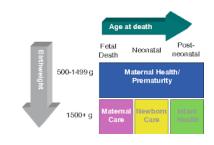
	Total	Black	Hispanic	White
2018	3.9	8.8	4.2	2.3
2017	4.5	9.4	4.8	2.7
2016	4.1	10.0	3.7	2.2
2015	4.8	9.7	4.6	3.0
2014	4.4	8.7	4.7	2.6
2013	4.5	10.6	4.0	2.6
NJ SHAD				

Table 4: Infant Deaths by Race/Ethnicity and Underlying Cause, NJ, 2017

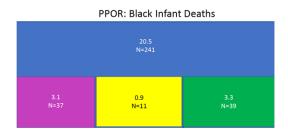
	Black		Hispanic		White	
	# (%) of 127 Black Infant deaths)	Rank	# (%) of 130 Hispanic Infant deaths)	Rank	# (%) of 120 White Infant deaths)	Rank
Low Birthweight	20 (15.7)	1	26 (20)	2	14 (11.7)	3
SIDS	17 (13.4)	3	3 (2.3)	6	18 (15)	2
Congenital Anomalies	19 (15.0)	2	28 (21.5)	1	20 (16.7)	1
Maternal Complications	9 (7.1)	4	9 (6.9)	3	8 (6.7)	4
Sepsis	6 (4.7)	5	3 (2.3)	6	4 (3.3)	6
Respiratory Distress	5 (3.9)	6	4 (3.1)	5	4 (3.3)	6
Placental/Cord complications	3 (2.4)	7	5 (3.8)	4	5 (4.2)	5

Table 5: Perinatal Periods of Risk Analysis (PPOR)

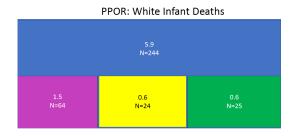
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В.



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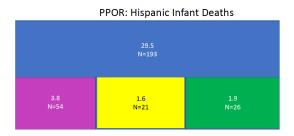


Table 6: Health Conditions and Care Before Pregnancy by Race/Ethnicity, New Jersey, 2013-2018

Pre-pregnancy Condition	Black	Hispanic	White
Diabetes	3.4	3.6	4.2
Hypertension	5.4	4.4	5.4
Asthma	13.0	6.5	9.4
Smoker	17.7	8.4	16.9
Anxiety	9.5	10.4	18.8
Depression	6.8	6.0	9.6
Physical Abuse	2.4	1.5	1.0
Received Regular check-ups	67.0	61.0	47.4
Received OBGYN Check ups	26.2	24.2	38.0
Had Family Planning visit	0.4	0.9	1.6
Dental Visit-cleaning	2.7	8.2	6.5
BMI-Normal	32.4	34	55.2

Pre-pregnancy Condition	Black	Hispanic	White
BMI Overweight	25.5	21.8	22.1
BMI Obese	33.5	20.0	15.9
Entered PNC late	29.4	24.0	11.8
Entered PNC as early as desired	77.5	85.4	91.1

Black Infant Mortality Rates by Municipality, New Jersey, 2005-2015

Table 7

COUNTY	TOWN	BIM
Atlantic	Atlantic City	20.0
Atlantic	Pleasantville City	18.3
Burlington	Willingboro Township	10.8
Camden	Pennsauken Township	16.5
Camden	Camden City	15.6
Camden	Winslow Township	12.5
Cumberland	Millville City	18.1
Cumberland	Bridgeton City	6.6
Essex	Newark City	11.4
Essex	Orange City	10.8
Essex	Irvington Township	9.1
Essex	East Orange City	8.3
Hudson	Jersey City	11.3
Mercer	Trenton City	16.3
Mercer	Hamilton Township	16.1
Passaic	Paterson City	10.5
Union	Elizabeth City	9.9
Union	Plainfield City	7.8
	sey Infant Birth-Death Datab artment of Health	ase,
Prepared by MCI Department of H	H Epidemiology, New Jersey lealth, April 2018	

Section I.4. Data Snapshot: Women's access to health care, social services, and supportive policy

Elizabeth S. Lee & Vijaya K. Hogan

To understand the policy dynamics affecting women in New Jersey, the Nurture NJ strategic planning team conducted nearly 30 interviews with policymakers across the state, asking which current policies most influenced maternal health, and which policies could influence maternal health in the future. In addition, in order to establish a baseline from which to gauge the impact of the Strategic Plan, the planning team conducted qualitative and quantitative research into the current state of New Jersey women based on the primary social determinants of health that could be impacted by policy changes and improvements. This brief snapshot offers a view into what factors affect the daily lives of women living in New Jersey today.

Healthy Women

For women of child-bearing age, considering pregnancy either over the short or long term, a number of factors are key in ensuring her health – access to housing,¹² healthy foods,³ stable economic supports,⁴ tax relief,⁵ paid leave,⁶ and a solid educational foundation.⁷

Healthy Foods

<u>Current Status</u>: The USDA estimates that, in 2017, 9.6 percent of New Jersey residents live in homes without consistent access to adequate food for everyone to live healthy, active lives.

<u>Relevant state agencies and programs</u>: Department of Human Services (Supplemental Nutrition Assistance Program (SNAP)), Department of Health (Women, Infants, and Children (WIC))

Housing

<u>Current status</u>: Approximately 25 percent of New Jersey renter households are extremely rent-burdened, paying over half their income toward the cost of housing. The figure rises to 51 percent for households making less than \$50,000; over 58 percent of New Jersey rental housing is unaffordable to households making \$50,000 or less, and 88 percent of New Jersey rental housing is unaffordable to persons employed full-time and making the minimum wage ("unaffordable" is defined as gross rent that would consume more than 30 percent of household income).

<u>Relevant state agencies and programs</u>: Department of Community Affairs (State Rental Assistance Program; Homelessness Prevention Program), Housing Mortgage Finance Agency

Education

<u>Current status</u>: Higher education in New Jersey is often just out of reach, including for women and parents. One million adults in New Jersey have completed at least some college credit but have not

obtained a degree.⁸ The majority of student borrowers default on their loans for amounts less than \$10,000.

A high number of individuals who default on their school loans do so for small amounts, such as \$7,000-\$10,000.

<u>Relevant state agencies and programs</u>: Office of the Secretary of Higher Education (Community College Opportunity Grant (CCOG) program, GEAR UP (Gaining Early Awareness and Readiness for Undergraduate Programs), New Jersey's Educational Opportunity Fund (EOF))

Earned Income Tax Credit

<u>Current status</u>: 23 percent of eligible residents do not participate in the Earned Income Tax Credit⁹; last year, the average credit in New Jersey was \$2,363.¹⁰

Relevant state agencies and programs: Department of Treasury EITC Info program

Paid Leave

<u>Current status</u>: The Department of Labor estimates that only 50 percent of birthing parents in New Jersey take advantage of paid leave, and the number of non-birthing parents taking paid leave is even lower.

Relevant state agencies and programs: Department of Labor

Access to Preconception Care

Current Status:

- In 2017, 85.1 percent of white women, 84 percent of Hispanic women, and 81.6 of Black women had a pap smear in the past three years (SHAD).
- In 2017, 84.4 percent of white women, 78.6 percent of Black women, and 65.3 percent of Hispanic women reported having a primary care provider (SHAD).
- In 2018, 34.6 percent of white women, 50 percent of Hispanic women, and 38.6 percent of Black women were using birth control at conception (PRAMS).
- In 2018, 56 percent of Black women, 78 percent of white women, and 44 percent of Hispanic women reported a healthcare visit in the year before pregnancy (PRAMS).
- Use of LARCs is considerably lower than prevalence nationally. For instance, between 2015 and 2017, about 1 percent of all female Medicaid beneficiaries aged 15-54 were using LARCs, as compared to 7 percent of women nationally in 2011-13.¹¹
- Relevant state agencies and programs: Department of Health

Equitable Care

Currently, women in New Jersey struggle with accessing care that is consistently equitable, respectful, and evidence based.

Access to Care

<u>Current status</u>: 30 percent of women eligible for Medicaid in New Jersey, or 9,345 beneficiaries annually, are eligible only through their pregnancy and 60 days post-partum. With approval from the legislature, New Jersey is currently pursuing an 1115 waiver with the Centers for Medicare and Medicaid Services (CMS) to extend coverage to 180 days, although federal approval is uncertain.

<u>Relevant state agencies and programs</u>: Department of Human Services, Familycare New Jersey

<u>Current status</u>: Undocumented women face particular challenges. The program to provide free or low-cost prenatal services to undocumented women in New Jersey is available through hospital-based women's health clinics and at Federally Qualified Health Centers (FQHCs) through New Jersey

Supplemental Prenatal Care. But the program's funding has been capped for decades and effectively runs out by the third month of each fiscal year. Once exhausted, hospitals and FQHCs continue to provide services as charity care, which is not compensated by federal or state sources.

Relevant state agencies and programs: Department of Human Services

Quality of Care

<u>Current status</u>: Women across the state speak of a profound lack of respect, time, and person-centered approaches necessary to provide meaningful healthcare. In addition, current best practices in quality care delivery do not account for culturally and socioeconomically feasible implementation of care and services.

The Department of Health presents regulatory barriers to midwives, who have demonstrated their ability to improve outcomes for vulnerable women, from attending births in hospitals. Midwives are licensees of the Board of Medical Examiners and, based on feedback from New Jersey stakeholders, should be able to practice in accordance with their training.

The state has one of the highest operative delivery rates in the US, indicating a high degree of medicalization of the birth experience.

New Jersey performs poorly when it comes to unnecessary surgical births and NTSV C-sections; only 16 percent of New Jersey birthing hospitals met the national target in 2016.

Interviews with stakeholders indicated a lack of knowledge about the potential benefits of midwives, and related low accessibility in Black and Latino communities.

None of the three existing birthing centers in New Jersey accept Medicaid insurance, limiting accessibility for low-income women. Their lack of partnership with the Department of Human Services has likely decreased the likelihood of this model spreading more widely.

Providers of color and in lower-resource neighborhoods are less likely to participate in value-based care arrangements. Directly addressing the social determinants of health increases the average cost of treating a patient, but can often lead to better health outcomes; by incorporating these types of supports into value-based care through technical assistance, progressive financial arrangements and proactive outreach, the state could help maintain and support providers in low-income communities.

Relevant state agencies/programs: Department of Health, New Jersey Perinatal Quality Collaborative, Department of Human Services

Environments and Institutions

The inequity continues for women of color once they have had their baby, and endangers the health of that child. Specifically, women lack access to postnatal support and the proper economic, social, and clinical conditions to ensure a healthy mom and baby.

Postpartum Behavioral Health Issues

<u>Current status:</u> Postpartum moms are at risk for a range of issues, including postpartum depression and substance misuse and abuse. Black women in New Jersey are more than three times as likely as white women to experience postpartum depressive symptoms, and those reliant on public programs (WIC, Medicaid) are more likely to experience them as well. Fathers are at risk for these symptoms, too—estimates of incidence of postpartum depression in males range from 5-10-percent.

<u>Relevant state agencies/programs</u>: Department of Health, Department of Human Services

Breastfeeding

<u>Current status</u>: While moms are struggling to manage their own health, making choices for the health of their infants can be even more challenging. The American Academy of Pediatrics recommends exclusive breastfeeding for the first six months followed by continued breastfeeding along with the introduction of solid foods through the end of their first year and beyond, but just 35.2 percent of New Jersey infants were exclusively breastfed at hospital discharge in 2016, and that rate decreased to 31.6 percent in 2018. Exclusive breastfeeding rates in New Jersey drop significantly after hospital discharge with only 22.8 percent of infants being exclusively breastfed at six months in 2016. Relevant state agencies/programs: Department of Health

Child Care

<u>Current status:</u> Without access to reliable quality childcare, parents face limits on their economic freedom. The Murphy Administration has made significant investments to address capacity issues facing parents seeking childcare in New Jersey. As of 2017, licensed childcare center capacity could only accommodate 27 percent of the infants and toddlers likely to need care¹²; in addition, the number of registered family childcare homes has been steadily declining, further reducing options. In fact, about 40 percent of New Jersey municipalities, particularly urban and rural communities, are considered "deserts" due to the lack of childcare for babies.

To build this capacity, the Murphy Administration has invested over \$100 million in increasing state childcare subsidy rates, decreased co-pays for families, and decoupled the infant and toddler childcare rates to account for different staffing and capital needs. As state leaders look to address infant health and the safety of babies and children while mothers are pregnant, investments in capital improvements, adjusting for minimum wage increases, and shared services for small businesses, are important options to consider.

Grow NJ Kids, New Jersey's Quality Rating Improvement System, is New Jersey's program to raise the quality of child care and early learning across the state. Grow NJ Kids gives child care and early learning programs resources to assess and improve their programs, while providing parents with information that allows them to evaluate the quality of programs and make the best choices for their child.

<u>Relevant state programs:</u> Department of Human Services, Department of Children and Families, Department of Education, Economic Development Authority

Table: Key Pre-Pregnancy Health Indicators, by Race/Ethnicity

Indicator	Black	White	Hispanic	Asian
Obesity	36.0	17.3	19.4	11.4
Overweight	25.5	22.4	24.4	15.8
Was Using birth control at conception	38.6	34.6	50	27.8
Unintended pregnancy	48.3	13.4	36.5	17.7
Any health care visit 12 months before pregnancy	55.9	78.4	44.9	55.7
Had a previous Preterm birth	17.2	11.4	19.9	11.9
Diabetes (before pregnancy)	4.8	3.7	2.4	3.5
Hypertension (before pregnancy)	11.2	5	4.5	3
Depression (before pregnancy)	7.5	8.8	6.9	2.5
Asthma (before pregnancy)	12.4	9.6	8.5	3.5
Smoking (before pregnancy)	15.7	13.2	6.3	3.6
Alcohol consumption (before pregnancy)	45.8	73.3	44.2	34.7
Unmarried	50.4	31.1	47.3	50
< Highschool education	9.8	14.7	13.9	20
Source: NJ PRAMS, 2018				

Section I.5. Issue in Focus: Adverse Childhood Events, Substance Use and Infant and Maternal Morbidity and Mortality

Vijaya K. Hogan & Elizabeth S. Lee

The Nurture NJ Strategic Plan is strongly guided by life course theory. It shows up most prominently in the Strategic Plan as a series of recommendations for actions that occur before and after pregnancy, i.e., over the non-pregnancy periods of the life course of women and children. Life-course theory gained prominence in the 1980s with the introduction of the Barker hypothesis, which stemmed from geographic analyses showing a strong correlation between high rates of infant mortality and high rates of specific chronic diseases. Barker argued that analyzing the problem and defining remedies required an understanding of the effects of past experiences and social context on social determinants of health (SDOH).^{1,2}

Barker suggested the existence of two critical changes that occur *in utero* that contribute to poor health outcomes in later life. The first is plasticity—a period when developing organs adapt to stressors in the fetal environment. These adaptations can help the fetus survive the immediate danger, but in the long term, the adaptation becomes a physiologic limitation resulting in chronic conditions later in life. The second is epigenetics—a response to external environmental stressors that causes a differential expression of genes that may also be protective in the short term, but maladaptive in adulthood. Life course, therefore, examines how the places people are born, grow, live, work, and age, contribute to their health outcomes; it searches for critical or sensitive periods of risk and for the effects of cumulative exposures.³ This is particularly compelling since the process of identifying the causal pathways and risks of adverse Black birth outcomes could potentially impact the elimination of other adult health disparities (including maternal morbidities and mortality) since infant outcomes are the foundation for adult health.

The World Health Organization (WHO) Commission on Social Determinants of Health considers the major contributors to health disparities to be the conditions in which people are born, grow, live, work, and age. In the US, Black people are more likely to be in socially and economically vulnerable positions. A number of studies have demonstrated that even while controlling for socio-economic status, racial and ethnic disparities are still found in health outcomes. For example, Black women in Illinois at the highest education level have worse low-birthweight rates than women of any other ethnicity at lower education levels. The process that determines social stratification leading to poorer health outcomes is rooted in history, and while it is not about "race" as a risk factor, scientific investigation has uncovered a body of knowledge that places racism, perceived acts of racism, poverty, social environmental degradation, and violence, into the etiological pathway. G-12 These manifestations of "social ecology" are the type that WHO describes as resulting in unfair and avoidable differences in health status.

Thus, one of the keys to understanding and addressing the extreme disparities in infant and maternal morbidity and mortality in New Jersey lies simply in understanding the role that history plays in shaping the present. What happened in the past has profoundly shaped the conditions of the present. The

history of the Atlantic slave trade, for example, has had a profound effect in shaping the economic development of the US, as well as in creating the extreme racial inequities in the distribution of that accumulated wealth. The effects of history can have equally profound effects on maternal and infant outcomes.

This is where adverse childhood experiences (ACEs) emerge as relevant factors in understanding the life course/historical impacts on maternal and child health and the disparities in these outcomes. ACEs are a mechanism for transferring risk across the life course from childhood to adulthood, and across generations from mother to child.

Adverse Childhood Experiences (ACEs) are stressful or traumatic events that occur before the age of 18. The most commonly cited ACEs include physical abuse, sexual abuse, emotional abuse, physical neglect, emotional neglect, parental incarceration, domestic violence, household mental illness, household substance misuse, and parental separation or divorce. Adverse childhood experiences are often coupled with adverse community environments, which rob the child of protective environments that may confer some resilience to the ACEs.¹³

ACEs may affect reproductive health through any number of biological changes that result from the stressful exposures during childhood. These changes can include compromised neuroendocrine and immune functions. Birth outcomes can be influenced indirectly through psychosocial pathways including elevated levels of stress and anxiety, tobacco and substance use, and exposure to adverse adult experiences.¹⁴

Individuals with at least four ACEs have been found to be at increased risk of all health outcomes compared with individuals with no ACEs. 15 The strength of association between ACEs and health differed depending on the outcome: effects were weak or modest for impacts of ACEs on physical inactivity, overweight or obesity, and diabetes; moderate for smoking, heavy alcohol use, poor self-rated health, cancer, heart disease, and respiratory disease (Odds Ratios of two to three); strong for sexual risk taking, mental ill health, and problematic alcohol use (ORs of more than three to six); and strongest for problematic drug use, and interpersonal and self-directed violence (ORs of more than seven).

Four or more adverse childhood experiences were found to be related to a 2-fold increased risk of experiencing any biomedical risk, and 5-fold risk of psychosocial risk during pregnancy. ¹⁶ A close response was found between the number of adverse childhood experiences and the extent of biomedical and psychosocial risk.

ACES in New Jersey. In 2016, more than 40 percent of children in New Jersey experienced one or more ACE. More than 18 percent experienced two or more. The rate is higher for Black and Brown children: 27 percent of African American and 22 percent of Hispanic children in New Jersey experience multiple ACEs.¹³

This figure may be higher if premature birth is considered an ACE. Premature birth may qualify as an ACE because it can result in disruptions in parent/child attachment and cause similar damage as ACEs. A baby born prematurely often spends that crucial time for attachment and development of neural pathways in the neonatal intensive care unit, or NICU. While research is still drawing connections to

attachment, being born preterm has long-term effects on areas such as cognitive development, relationships, academics, and mental health. It is possible these issues are, in part, the result of limited early attachment opportunities for preterm babies while their system is also in distress without positive counterbalancing forces.¹⁷⁻¹⁹

Substance Use in New Jersey. As stated earlier, high substance use can be one adult consequence of the experiences of ACEs in childhood. The most common substances abused by individuals in New Jersey seeking treatment are alcohol and heroin²¹ —both of which have significant impacts on maternal and infant health. The opioid epidemic had finally showed signs of slowing before the COVID-19 pandemic hit, but the state has once again seen a spike in overdose deaths. Despite drug-related deaths leveling off in 2019, overdose deaths in the first half of 2020 were 17 percent higher than in 2019.²² For those experiencing increased stress during the conjoined crises of the COVID epidemic in communities of color, as well as the groundswell of racial injustice and related protests, the risk of substance abuse becomes even greater.

From the New Jersey ACES Report: "ACEs, however, are not inevitable, nor do they have to determine the destiny of a child who experiences them. ACEs can be prevented, and when they do occur, concrete steps can be taken to help children heal." ²³

"More recent studies have shown a specific correlation between ACEs and opioid addiction. For example, a 2016 study demonstrated a clear dose response relationship between the number of traumatic experiences and increased risk of prescription drug misuse in adults. Individuals who reported five or more ACEs were three times more likely to misuse prescription pain medication and 5 times more likely to engage in injection drug use. Another study found that over 80% of the patients seeking treatment for opioid addiction had at least one form of childhood trauma, with almost two-thirds reporting having witnessed violence in childhood.6 Among the different forms of adverse childhood experiences, sexual abuse and parental separation (for women) and physical and emotional abuse (for men) appear to be particularly highly correlated with opioid abuse.7 In one study, although childhood trauma alone did not predispose the development of opioid addiction, individuals with high childhood trauma scores were more likely to display antisocial behavior and to have complicated addiction histories.

In addition, studies have shown that individuals who have experienced childhood trauma are more likely to report chronic pain symptoms that interfere with daily activities and are more likely to be prescribed multiple prescription medications making them more likely to seek opioids for pain relief in adulthood⁹ and creating a likely pathway to addiction. Similarly, veterans of the wars in Iraq and Afghanistan who are diagnosed with PTSD are significantly more likely to receive opioids for pain, to receive multiple and higher doses, and to experience adverse clinical outcomes than those without PTSD.²⁴

The effects of substance abuse on maternal and infant health have been well documented, including increased infant mortality, and severe complications.²⁵ In addition, across the country, including New Jersey, maternal deaths in the year following pregnancy have been on the rise, and increasingly linked to

substance use. Recent reviews have found opioid use to be the leading cause of increases in pregnancy-associated deaths in New Jersey ²⁰ and as such are a critical risk factor to be addressed.

In interviews, community stakeholders in the state expressed that stigma was a major barrier to seeking trauma-informed care, especially for women with substance or opioid use disorder. Rather than adopting a universal screening and referral to care model, many providers assign women to "certain" providers or treat them in a manner which only further deters treatment for the disorder. For women who are able to access treatment, the support and access drops off significantly after they deliver their baby, especially for the 10,000 women in New Jersey every year who lose access to Medicaid six weeks after delivery. A recent study showed that pregnant women face barriers due to availability of treatment and cost.²⁶

In addition, women with substance use disorder are more likely to struggle with other social determinants of health, including access to stable housing, and economic security, which impact their health and that of their baby. While small programs across New Jersey are providing housing for women with substance abuse disorder, including during the period of their pregnancy (Catholic Charities in Trenton, Center for Great Expectations in Patterson) these programs need to be scaled and supported.

Addressing ACES and Substance Use in New Jersey: The Nurture NJ Strategic Plan.

To address ACEs on an individual level, ensure use of trauma-informed models that strengthen the cognitive, emotional, behavioral, physical, and spiritual competencies of each client so that they can live meaningful lives. Promoting and supporting positive father involvement in pregnancy, childbirth and parenting, can also serve as an effective buffer against ACEs. On a population level, ensure that the contexts, environments, and resources in communities provide buffers against the experiences of ACEs, and provide the protective supports to ensure resilience against their negative effects. Both of these approaches form the basis of the recommendations included in this Strategic Plan.

While many of the recommendations in the Strategic Plan will support and address issues faced by women with substance use disorder, targeted effort for this population is certainly warranted. First, access to opioid use disorder treatment is critical. The American College of Obstetricians and Gynecologists (ACOG) recommends that pregnant women do not stop taking an opioid drug suddenly during pregnancy if they are dependent on it. Instead, a drug like methadone or a buprenorphine product may be helpful, especially when introduced in the second trimester, to decrease the risks of opioid withdrawal and danger to the fetus. Increasingly, it is becoming best practice to prescribe Suboxone, which can be administered at home and does not require daily visits to a methadone clinic. However, it is highly unlikely that access to opioid use disorder treatment medications alone will facilitate lasting maternal and infant health. Comprehensive, patient-centered care that takes into account the factors impacting the woman's health is critical to long term recovery and health. Strengthening connections between community-led organizations and healthcare providers through cross cutting community power-building will help to create this permanent continuum of care.

The Division of Mental Health and Addiction Services (DMHAS) serves as the Single State Agency (SSA) for Substance Abuse and the State Mental Health Authority (SMHA) as designated by the

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U.S. Substance Abuse and Mental Health Services Administration (SAMHSA). The Division oversees New Jersey's adult system of community-based behavioral health services.

Section 1.6. History of Racism in the United States

Pauline E. Brooks & Patricia H. Karimi-Taleghani

In order to better understand the powerful forces at work behind unequal outcomes in maternal and child health, it is important to ground ourselves in the history.

While New Jersey is a truly diverse state, it is also deeply segregated. A nationally groundbreaking court decision in 1975, known as the Mount Laurel doctrine, prohibited municipalities in the state from using zoning powers to discriminate against affordable housing. Unfortunately, from 1999 to 2015, the state government failed to enforce these requirements, so over those nearly two decades, the segregation grew worse. While racism is understandably difficult to measure, a study released in 2015 analyzing internet data found that New Jersey was "more racist than average." The Southern Poverty Law Center tracks 21 active hate groups in New Jersey.

Racism contributes to the many long-existing, well-documented racial disparities in the US. Racial disparities refer to the presence of differences in treatment and/or outcomes for different racial groups. Dating back centuries and up to the present day, racial disparities appear in virtually every sector and indicator of wellbeing in US society: e.g., health, education, employment, wealth, incarceration, housing, etc. With few exceptions, centuries of patterns of racial disparities show white people in the US as an ethnic group experiencing more of the desirable, advantageous, and favorable treatment and outcomes of the society, and Black people and many other people of color, lower income, women, and rural people in the US experiencing more of the undesirable, disadvantageous, and unfavorable treatments and outcomes. Disparities in any one sector intersect with disparities in other sectors, producing compound effects.

What Is Racism?

Racism is not limited to any one nation. It has been and is a worldwide problem both within and between nations. Racism often intersects with other hierarchies, such as gender and class hierarchies (intersectionality). Very importantly, racism is about power—it is an assertion of power and dominance. Racism can be intentional, unintentional, conscious, unconscious, or dysconsciously perpetrated. What follows are merely a few of the many terms and concepts used in defining, naming, understanding, and addressing racism.

(1) UNESCO Definition

An internationally crafted definition by the United Nations Educational, Scientific, and Cultural Organization, still in use today internationally, captures much of the breadth and extensiveness of racism:

"Racism includes racist ideologies, prejudiced attitudes, discriminatory behaviour, structural arrangements and institutionalized practices resulting in racial inequality as well as the fallacious

notion that discriminatory relations between groups are morally and scientifically justifiable; it is reflected in discriminatory provisions in legislation or regulations and discriminatory practices as well as in anti-social beliefs and acts; it hinders the development of its victims, perverts those who practise it, divides nations internally, impedes international co-operation and gives rise to political tensions between peoples; it is contrary to the fundamental principles of international law and, consequently, seriously disturbs international peace and security."¹ [...]"Any theory which involves the claim that racial or ethnic groups are inherently superior or inferior, thus implying that some would be entitled to dominate or eliminate others, presumed to be inferior, or which bases value judgements on racial differentiation, has no scientific foundation and is contrary to the moral and ethical principles of humanity."²

(2) Structural racism focuses on the organizational arrangements of a society's institutions, systems, networks, and dominant narratives, and how these differentially disadvantage or advantage people of different racial groups. In the grander scheme of things, society's institutions, systems, organizations, and dominant narratives work in concert with one another. They fit together. They work together. And, the concerted operations of these large physical and conceptual structures historically have served to reproduce and justify the racial hierarchy.

"...structural racism is meant to encompass the dynamics present across a broad range of institutions. Moreover, structural racism is intended to acknowledge the broad set of historically developed ideas, values, and morals that make racism seem natural, inevitable, and acceptable to the vast majority of the body politic. A structural racism framework helps us consider not only the agents of racial discrimination but also the dominant discourses that permit such discrimination to go unchallenged."³

Example. There continues to be a high incidence of low infant birth weight among Black infants. Mainstream health policy and program planners, even researchers, often start with society's present structures and arrangements as givens; these things are not questioned. Attention shifts instead to ideas that imply that whatever is wrong lies with Black Americans— that Black women do not go for prenatal care, they eat the wrong foods, smoke, drink alcohol, are stressed, etc. Then authorities within the system (that perpetrates racial inequities in the first place) propose solutions: go earlier to the doctor for prenatal care, learn how to prepare better meals, take pregnancy vitamins, do not drink alcohol, do not smoke, etc. All of these are important, no doubt. Yet, seldom are past or present inequities within the structures, or organizing and arrangements of society focused upon. Little or no attention is placed on examining various structures of the society that have historically operated differently for Black Americans compared to white Americans. Without considering structural and systemic factors, efforts to eliminate inequitable racial treatment and outcomes will be exercises in merely maintaining the status quo, making people of color and whites feel more comfortable with the white racial hierarchy.

(3) **Procedural racism** involves the use of devices such as cultural and institutional rules to limit and invalidate opportunities for those individuals and groups historically identified as "inferior" races. Delgado and Mohanty offer as examples that the law establishes difficult-to-meet requirements, including proof of intent, that make it almost impossible to "prove" racism.^{3, 4} Simultaneously, the law

places limitations on the types of relief that victims of racism can receive and on attorneys' fees. Authorities may even reduce their financial supports for agencies that litigate racism cases. Some laws remain "color-coded," just differently than in the past:

"The law and legal institutions normalize white advantage by articulating and enforcing cultural norms, which help to maintain racial hierarchy in the United States".⁵

Example. In the 1930s and 1940s, Fair Housing legislation passed by the US Congress banned racial discrimination in housing. Prior to this, the US Congress had repeatedly blocked efforts to rid housing markets of racial bias. However, the provisions for enforcement of anti-racial discrimination in fair housing legislation were gutted. This allowed for implementing-agencies to narrowly interpret what little enforcement there was in the legislation. Similarly, during this same period, people of color were largely left behind or excluded from other sweeping legislation that brought in social welfare protections for old age, jobs, asset building, economic security, and opportunities for acquiring a middle-class way of living.⁶

Example. Laws or programs may make it possible for a mother in poverty to get a job, but she then loses her childcare supplement. Without the childcare supplement she cannot afford to work, yet the childcare supplement requires that she look for work. In this instance, families in poverty are trapped by policies and procedures.

(4) **Institutionalized racism** is one of the more common manifestations of racism.^{7,8} One of three types of racism defined by Jones, it can be a component within any institution.

"...institutionalized racism is defined as differential access to the goods, services, and opportunities of society by race. Institutionalized racism is normative, sometimes legalized, and often manifests as inherited disadvantage. It is structural, having been codified in our institutions of custom, practice, and law, so there need not be an identifiable perpetrator. Indeed, institutionalized racism is often evident as inaction in the face of need."

Example. Though different Asian populations have their unique histories, languages, and cultures, they frequently experience something in common in the US related to their "race." Asian Americans "...have been and continue to be viewed as almost identical by American society. In the American racial order, Asian Americans are generally ignored by policy makers and institutional leaders. They have been convenient scapegoats in times of economic recession and social crisis. They continue to be excluded from curricula, media representations, and popular culture. They receive lower wages than their European American counterparts for the same work, even though their education and training are equal or greater. And they encounter a "glass ceiling" in employment created by racial stereotypes and prejudices. They also continue to face anti-immigrant sentiment and actions despite the fact that they have been born here or are even third- or fourth-generation Americans." ¹⁰

(5) **Personally-mediated racism** can be traced to an individual or individuals. Its source has a face. It can be perpetrated intentionally or unintentionally and can entail acts of omission or commission. This form

of racism contrasts with impersonal types of racism, such as institutional, structural or systemic racism that are anonymous.⁹

"Personally mediated racism is defined as prejudice and discrimination, where prejudice means differential assumptions about the abilities, motives and intentions of others according to their race, and discrimination means differential actions toward others according to their race."

This is the form of racism that most often comes to mind when people in mainstream society use the term racism: For many people, racism means a specific individual (a person) or set of individuals (specific persons) saying or doing things that can be labeled racist.

Examples: a white waiter intentionally refuses to give service, or gives poorer service, to customers of color; an owner of a store unconsciously hires and promotes whites only, even when applicants of color are better qualified, or have earned the promotion; a medical doctor gives less time and attention to remedying health problems of patients of color compared to the time and attention given to white patients, or the doctor makes assumptions about substance use, sensitivity to pain, knowledge of the patient's own body, following prescription regimes, or the like based on stereotypic thinking concerning patients of color.

Personally-mediated racism may take the form of someone making decisions consciously or unconsciously based on race/culture/ethnicity concerning opportunities for someone to be: hired, admitted into college, given entry into a nightclub, receiving timely and helpful police or ambulance services, being accepted into a fraternity, being included in discussions and decision-making concerning healthcare for one's own community, etc.

(6) **Color-blind racism** refers to a kind of socially acceptable shield of apparent decency and openness that, in actuality, serves to protect white privilege. In color-blind racism, whites and white privilege claim no responsibility for today's racial disparities. The idea is that there is no white wrongdoing mixed up in any of today's racial inequalities.¹¹

Examples: Whites claim that they see "people," "human beings" and not color. They use non-racial analyses. Contemporary color-blind theories and perspectives settle on such things as:

"...social class, cognitive ability, lack of work ethic or morality, human capital deficits, spatial mismatch, and family structure. While these theories are not exhaustive, they are all "popular" explanations for Black disadvantage. Despite their popularity they are only weakly or incompletely supported by empirical research. The scientific research on racial inequality overwhelmingly supports the idea that racism is the primary cause of Black disadvantage. The popularity of these theories can be interpreted as ideological defenses of "white privilege." 12

Use of terms like "explicit bias" or "implicit bias" as substitutes for "racism" are contemporary examples. When used to substitute for racism, these terms omit anything about race, racial history, racial inequities, racially unequal environments, treatments and outcomes, the racial hierarchy, and the pervasiveness and saturation of racism throughout US society. In the end, white privilege and the status

quo are maintained. These behaviors, by sometimes well-intentioned persons, are part of what Bonilla-Silva as "the curious enigma of 'racism without racists'". ¹¹ Kendi's point that the opposite of racism is anti-racism is lost on the color-blind racist. ¹³ Given the history of the US, blindness to race not only denies or attempts to erase the cultures and identities of people of color but also serves to permit racism's continuance.

(7) **Epistemological racism** - "...a tenet of Western Positivistic research that marginalizes the worldviews of minorities and people of color". ¹⁴ Epistemological racism creates circumstances so that the voice and agency of communities and people of color are excluded, omitted, ignored, considered unimportant, silenced, or otherwise sidelined or controlled. Their voices, issues, and concerns do not get on the agenda of those who make the decisions. They are silenced concerning the identification of what is important, why, what to do about it, when, how, with what resources, and with what desired outcomes. So, too, their worldviews, historical experiences, values, and ways of conceptualizing and organizing knowledge are excluded from discussions, problem identification, resolutions, even history.

Information and language that consciously, unconsciously, or dysconsciously support the "master narrative"¹⁵ of white over people of color dominate discussions in the mainstream. This master narrative influences how discussions are framed, who gets to speak and be heard, and the specific types of messages that are repeatedly broadcast by echo-chambers for public consumption.

Example: Whites will often create their own versions of the issues that people of color bring forward—that is, whites make the issues fit within the existing dominant worldview, language, and racial hierarchy. For instance, the full meaning of cultural diversity in the field of health in the late 1990s was reduced to mean "language access." Such an extremely narrow view of culture and health fails to consider many things, including that English-speaking people may also have different cultural backgrounds (e.g., Black American-, Latinx- and other English-speaking cultural/racial communities) concerning health and wellbeing. It also fails to recognize that culture involves far more than translating from one language into another, that there may not be equivalent meanings between different cultures, and that different cultures may use very different knowledge sets concerning health. For instance, Western medicine and Eastern medicine operate on entirely different cultural, scientific, and health principles. Racial equity has been reduced in some circles to mean diversity and inclusion and not the desired structural changes that diversity and inclusion should promote.

Section I.7 The Science: Pathways of Racism's Impact on Health

Vijaya K. Hogan, Pauline E. Brooks, & Diane L. Rowley

	Pathway	Description	Examples	References
1.	Institutional pathways	Policies, procedures and practices which reduce or inhibit access to conditions of life that support health; for example; limit access to jobs, health care, quality housing, quality education, right to vote	 Redlining is a policy in housing and lending that limited the neighborhoods where Black people could live Black men are more likely to be arrested and convicted for similar crimes committed by white men, and are given more severe sentences People with criminal records are unable to vote in most states African Americans are incarcerated in state prisons at a rate that is 5.1 times the imprisonment of whites. In five states (lowa, Minnesota, New Jersey, Vermont, and Wisconsin), the disparity is more than 10 to 1. In twelve states, more than half of the prison population is black: Alabama, Delaware, Georgia, Illinois, Louisiana, Maryland, Michigan, Mississippi, New Jersey, North Carolina, South Carolina, and Virginia. Maryland, whose prison population is 72% African American, tops the nation. African Americans are more likely than white Americans to be arrested; once arrested, they are more likely to be convicted; and once convicted, they are more likely to face stiff sentences. Black men are six times as likely to be incarcerated as white men and Hispanic men are more than twice as likely to be incarcerated as non-Hispanic white men. meta-analysis of callback rates from all existing field experiments showed evidence of discrimination against both black and Latino (job) applicants. Since 1990 white applicants received, on average, 36% more callbacks than black applicants and 24% more callbacks than Latino applicants with identical résumés. There has been no change in hiring discrimination for Black Americans in the past 25 years After responding to 1,300 classified ads with dummy resumes, the authors found blacksounding names were 50 percent less likely to get a callback than white-sounding names with comparable resumes. 	Williams, D. R., & Mohammed, S. A. (2013). Racism and Health I: Pathways and Scientific Evidence. The American behavioral scientist, 57(8), 10.1177/0002764213487340. https://doi.org/10.1177/0002764213487340 Nellis, A. The Color of Justice: Racial and Ethnic Disparity in State Prisons. June 14, 2016 https://www.sentencingproject.org/criminal-justice-facts/ Quillian, Pager et al. Harvard Business Rev, Oct 2017 Marianne Bertrand and Sendhil Mullainathan, "Are Emily and Greg More Employable Than Lakisha and Jamal? A Field Experiment on Labor Market Discrimination," American Economic Review, September 2004.

	Pathway	Description	Examples	References
2.	Cultural Pathways	Implicit bias/acting on unintentional beliefs that one group is lower on a perceived social hierarchy Internalized belief in a hierarchy of human value by oppressed peoples	Higher rates of invasive operative procedures for Black women; belief that "Black women can take more pain than other women" Internalized racism/oppression can result in harmful coping behaviors, increased stress and loss of agency Half of white medical trainees believe such myths as black people have thicker skin or less sensitive nerve endings than white people.	Hoffman, KM et al. Racial bias in pain assessment. Proceedings of the National Academy of Sciences Apr 2016, 113 (16) 4296-4301; DOI: 10.1073/pnas.1516047113
3.	Physiologic pathways via psychosocial stressors	Experience of racism and discrimination correlate with physiologic markers of stress and related diseases Racial discrimination may accelerate aging in children and adults.	External stressors can permanently alter physiological functioning. Racism increases the volume of stress one experiences and may contribute directly to the physiological arousal that is a marker of stress-related diseases. increased experiences with racial discrimination is associated with more rapid shortening of telomeres, an indication of cell aging.	Clark R, Anderson NB, Clark VR, Williams DR. Racism as a stressor for African Americans: a biopsychosocial model. Am Psychol. 1999;54:805–816. [PubMed] [Google Scholar] Henry JP, Liu J, Meehan WP. Psychosocial stress and experimental hypertension. In: Laragh JH, Brenner BM, eds. Hypertension: Pathophysiology, Diagnosis and Management. New York, NY: Raven Press; 1995:905–921. Chae, D. H., Wang, Y., Martz, C. D., Slopen, N., Yip, T., Adler, N. E., Fuller-Rowell, T. E., Lin, J., Matthews, K. A., Brody, G. H., Spears, E. C., Puterman, E., & Epel, E. S. (2020). Racial discrimination and telomere shortening among African Americans: The Coronary Artery Risk Development in Young Adults (CARDIA) Study. Health Psychology, 39(3), 209–219.
4.	Historical Oppression	Historical trauma is "the cumulative emotional and psychological wounding over the lifespan and across generations, emanating from massive group trauma." -Dr. Maria Yellowhorse-Braveheart	"I think you're dealing with generations of people who have been damaged by colonialism, and the way that we have been treated by the dominant culture makes you feel dispirited. You feel devalued and so people will turn to things like addictions as a way of coping, of self-medicating, of not really wanting to be here because their situation is just so intolerable."-Dr. Cornelia Wieman, M.D. FRCPC Transgenerational epigenetic inheritance is the transmission of epigenetic markers from one organism to the next (i.e., parent—child transmission) that affects the traits of offspring	(Kuzawa and Sweet 2009

	Pathway	Description	Examples	References
		embodiment of inequality transmitted through epigenetic influences Historic oppression has impact when the past continues to have impact in the current time. Collateral consequences are one form of this.	without alteration of the primary structure of DNA (i.e. the sequence of nucleotides. Maternal experiences of stress during pregnancy can affect fetal environments altering the fetal metabolic and physiologic development Incarceration can impose a lifetime economic sentence as barriers to loans, scholarship, housing, jobs, voting rights are constructed, disenfranchising formerly incarcerated from the resources needed to protect health	
5.	Direct deprivation of Life	Black men's mortality risk for death by police (1.9 and 2.4 deaths per 100 000 per year), is over twice the rate for white men; Latino risk is between 0.8 and 1.2, and White risk is between 0.6 and 0.7.	Extra-judicial killing of men and women of color, e.g. George Floyd, Breonna Taylor, Sandra Bland and countless Native American deaths	Frank Edwards, Michael H. Esposito, and Hedwig Lee, 2018: Risk of Police-Involved Death by Race/Ethnicity and Place, United States, 2012–2018 American Journal of Public Health 108, 1241_1248, https://doi.org/10.2105/AJPH.2 018.304559
6.	Healthcare	Black patients don't receive the same treatment as white patients	After surgery Black children are more likely to die than white children. African American premature infants are less likely to receive surfactant to treat respiratory distress syndrome	https://www.scientificamerican.com/article/after-surgery-black-children-are-more-likely-to-die-than-white-children/?amp=true Howell EA, Holzman I, Kleinman LC, Wang J, Chassin MR. Surfactant use for premature infants with respiratory distress syndrome in three New York city hospitals: discordance of practice from a community clinician consensus standard. <i>J Perinatol</i> . 2010;30(9):590-595. doi:10.1038/jp.2010.6

SECTION II.

Building an Ecosystem that Supports Maternal and Infant Health and Equity in New Jersey



Section II.1 The Nurture NJ Ecosystem

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The positive vision Nurture NJ presented as the cornerstone of the Strategic Plan is operationalized as the "Ecosystem Map." The Ecosystem Map is a vision of what conditions would need to be built in each community to ensure that the health outcomes sought by Nurture NJ can be achieved. The Nurture NJ Ecosystem can also serve as a playbook that can choreograph the actions of multiple stakeholders who are working within and across their field to build this common vision.

The objectives of Nurture NJ are to:

- Achieve racial equity in maternal and infant health
- Improve the health and well-being of all mothers
- Improve the health of infants and ensure the environment for optimal growth and development
- Make New Jersey the safest place in the country to give birth

While making New Jersey the safest place to give birth in the US is achievable, this will require a reenvisioning of what elements are essential to support the health and well-being of mothers and infants. Fundamental to this transformation is a commitment to health equity across all racial/ethnic groups and in every aspect of the health and social service systems in New Jersey, and a commitment to staying the course over the long term needed to reach these goals. Actualizing these commitments requires educating all stakeholders that optimal maternal and infant health is not merely a result of high-quality medical care but is also determined by complex social and structural forces that current systems of clinical care and public health are not effectively set up to address. Remediation of the complex social problems influencing health will require a unified effort across a wide range of both public and private systems working collectively and holistically to tackle the complex structural challenges that create inequities and adverse health. However, unless all of the appropriate stakeholders (health, housing, transportation, employment, food systems, etc.) are acting in concert, solutions may end up being counterproductive to the achievement of desired outcomes. Because the many challenges families face intersect with each other, the solutions in one arena must avoid collateral consequences in another. For example, families are often put into a position where they must make difficult choices among social needs (e.g., a job vs affordable daycare) when a both/and solution should be sought for the most effective impact. Without a roadmap guiding toward specific desired outcomes, stakeholders can easily veer off track as they strive to wrestle with the latest emergent health or social challenges. To ensure a comprehensive, efficient and successful approach, a unified "map" designed for Nurture NJ has been developed, referenced here as the maternal health "Ecosystem Map." This paper describes the rationale for, and the development and use of, an Ecosystem Map as an organizing force for attaining the objectives of Nurture NJ.

Disrupting the status quo: defining a novel approach. Getting to the envisioned future of New Jersey from the current situation may seem challenging if stakeholders consider one problem at a time, where

each "problem" represents a different aspect of a woman's life. The current system tends to silo discrete problems and address them in isolation from each other. While it seems counterintuitive at first, dissociating a problem from its larger context ignores the interdependencies that exist among discrete problems and often places undue burdens on the population being served. Families end up with their lives governed by a plethora of "programs" with their concomitant rules and requirements and find themselves making sacrifices in one area to accommodate a "solution" for another problem.

"Don't help me from one side and take from the other (side). I need my job to pay my rent and light bill, etc...but then, the paycheck means I don't qualify anymore for childcare. Without childcare, how can I keep my job?"

NJ female Resident, 2020

The COVID-19 pandemic serves to bring this challenge into sharp focus. For example, low wage workers are required to return to work in the face of the coronavirus pandemic; risks which may seemingly address the problem of a flailing national and/or personal economic situation. But, for many workers this discrete "solution" does not consider the intersecting challenges that face women with children—closed schools, a lack of safe childcare options, the increased risk of infectious exposure in public spaces, and responsibility to care for elders in the household, among other factors. If the problem is not addressed *holistically*—that is by considering all of these challenges simultaneously—harm ultimately results and is usually born by those who are most marginalized. Approaches to health must be based on the fact that women have multiple lived experiences including being workers, women with gendered responsibilities in the home, members of a group that bear the stresses of racial maltreatment without allies or assistance, and, in some cases, being a member of a low-resourced family or community who has a lot of adverse exposures.

Getting to the envisioned future for a healthy New Jersey requires a holistic and creative approach where the decisions, actions, policies, and interventions are attuned to the intersecting challenges women face. This requires thinking very differently about how systems are organized and function. The positive vision Nurture NJ presents as the cornerstone of the Strategic Plan and operationalized as the "Ecosystem Map" is a vision of what conditions would have to be in place to ensure the health outcomes sought by Nurture NJ can be achieved.

Nurture NJ Maternal and Infant Health Ecosystem Map

-		Prenatal care, labor & delivery,	Postpartum, early childhood,	
Timing	Before pregnancy	postpartum	throughout life course	
KEY OUTCOME:	HEALTHY WOMEN	EQUITABLE SERVICE & CARE	SUPPORTIVE ENVIRONMENTS & INSTITUTIONS	
		RACIAL EQUITY		
		TY POWER BUILDING AND E	NGAGEMENT	П
		ULTISECTOR COLLABORAT	ION	<u> </u>
	Mindset Shift	Mindset Shift	Mindset Shift	Ξ.
	Whole-life approach to women's health, not only during pregnancy	Accountability for the health and safety for all women, especially those impacted by	Holistic solutions that address population-level problems	† 2 2
	Public Policy	social and historic factors	Public Policy	<u>1</u>
	Application of Health	Public Policy	Health Equity in All Policies and Practices at the	<u>-</u> -
	Equity in All Policies and Practices standards, intersectional design and implementation frame	Health Equity in All Policies and Practices across funding and policy decisions	population-level to guide policy, intervention and funding	
		Research	Research	Ď
	Research Innovative and community-grounded to assess the impacts of the equity-based Ecosystem model on women's health	Quality improvement, monitoring, & evaluation and implementation science driven by community-grounded needs	Evidence bæe of strategies to remediate and repair social and historical risks developed through community-grounded reæarch	Equity and Improved Maternal and Infant
	Institutional & Structural Change	Institutional & Structural Change	Institutional & Structural Change	<u> </u>
	"Equity-integrated" designation process for agencies, organizations and businesses	Capacity development to create designated equity- integrated organizations	All agencies and public and private organizations designated "equity-integrated" institutions	and In
	Social Determinants of Health	Social Determinants of Health	Social Determinants of Health	fan:
	Access to resources to achieve and maintain health	All environments where people live, work, play, study and seek help facilitate health	En incomment and trans	Outcomes
	Individual	Individual Intervention & Care	facilitate health	
	Intervention & Care		Individual Intervention & Care	₹
	Expansion of coverage and payment strategies to make women's preventive health care available to all women	Health system accountability for addressing social and preventive factors, including through coordinated follow-up with community supports	Full community participation in learning, critical analysis and civic engagement	DO

Developing the Ecosystem Map

The Ecosystem Map was developed in stages and is intended to be an adaptive document. The first stage involved synthesizing the literature on contributing factors to inequities, morbidity and mortality, and organizing this into a frame. The next stage consisted of working with community stakeholders (providers, women, etc.) to modify the framework based on their experiences, history, and aspirations. This stage will be ongoing to reflect changes in community understanding of the dynamics of what contributes most to the health of the community. The third stage will be the active planning and implementation to build the ecosystem so that all of the components of it form the context of every community and is available to every woman in New Jersey.

Understanding the Ecosystem. Maternal and Child Health (MCH) outcomes are determined by health status before, during, and after pregnancy. As such, the ecosystem map is subdivided to map these time periods separately. Each column represents one of these time periods.

To acknowledge further complexity of the landscape, there are multiple payers, providers, and systems that are responsible for achieving different aspects of maternal and infant health. The complement of providers and systems may also vary by life course period. The types of services include: women and girls' general health and wellness care, preconception care, prenatal care, prenatal education, prenatal services (e.g., nutrition or high risk care), social services, home visiting, peer support, mental health services, labor and delivery, breastfeeding preparation, breastfeeding support, postpartum care—and each can be provided through different systems and different providers. These services are grouped into their relevant life course time periods (before pregnancy, during pregnancy/L&D), and after pregnancy).

The achievement of sustained reductions in maternal mortality and achievement of equitable outcomes may take a long time to unfold, and the ultimate outcome depends on the achievement of three subgoals—defined as critical but more *proximal* targets to the achievement of the Nurture NJ outcomes. These proximal outcomes include: Healthy Women, Equitable and Quality Service and Care, and a Supportive Environment to sustain health postpartum and beyond. These are achieved and measurable in a shorter time frame and are necessary achievements along the path to improved maternal and birth outcomes and equity. The Ecosystem thus redirects focus from the long-term outcomes toward the achievement of these more proximal ones.

Healthy Women. To accomplish the primary goal of improved maternal and birth outcomes and the reduction of inequities, improving women's overall health is foundational. The Perinatal Periods of Risk Analysis (PPOR) reveals that the majority of infant deaths in all race/ethnic groups occurs as a result of factors that occur during pregnancy and are best prevented primarily before a woman even knows she is pregnant. The prevailing medical and service provision culture emphasizes women's health mainly in the context of reproduction. Thus, most attention and services are rendered during gestation, with some current attempts to expand to a "preconception" period. A growing body of scientific evidence supports the notion that even expansion into the preconception period may be too narrow a time window in which to achieve any significant impact on women's reproductive outcomes, but can result in some control over adverse health conditions that may affect a pregnancy outcome. Early life course

exposures seem to predispose adult women to decrements in reproductive potential. For example, women exposed to traumatic shocks in childhood (e.g., sexual abuse or foster care placement) have significantly elevated risk of preterm birth compared to appropriately matched controls. This time period is suited for working with women of reproductive age to understand their health strengths and risks and begin to bring the risk under control.¹⁻²⁵

Equitable and quality service and care. The second relevant time period in the ecosystem occurs during pregnancy and encompasses prenatal care and related services, as well as labor and delivery. The related services can include all social services, mental health, transportation, housing, etc. Because prenatal care for the most part consists of expectant management—watching and addressing problems as they are identified—the issues addressed during this time period are generally remediation type services and intervention that mitigate immediate harm to the pregnancy. The timing of access and quality of care once care is accessed are important components of this outcome. Most importantly, evidence-based and equitable care are key qualities of the care component and must be structured into the delivery process for all services.

Supportive environment to sustain health postpartum and beyond. The third time period in the ecosystem map is the period after a pregnancy. A significant shift in ideology away from an emphasis on women's health solely as relates to reproductive potential to a fully realized life course approach to achieve a population of healthy women is necessary to achieve sustained improvements in maternal reproductive and birth outcomes. There is emerging evidence that experiences in childhood and across the life course can affect reproductive potential, thus a need to ensure health across the life course. As such, the third proximal outcome centers on the achievement of an ongoing supportive environment and context that extend beyond the pregnancy and postpartum periods, to cover the entire life course for both women and their infants. Women and their families should not have to live inside a safety net for their whole lives. Instead, their communities should ensure that the places where they live, work, play, shop, worship, learn, and recreate are always promoting, and never inhibiting, equity and health. This period outlines the contexts needed to ensure women have what they need to live healthy lives.

Ecosystem Development: Action Areas to Achieve Outcomes

There are nine action areas that affect all life course areas. Three of these action areas—racial equity, community power building and engagement, and multisector collaboration—are conceptualized as actions which crosscut all three life course areas and should be approached as an overarching structure to all life course areas. The remaining six action areas—mindset shifts, public policy, information for decision making, institutional and structural change, social determinants of health care, and individual care—are common across the columns but may be operationalized differently in each.

Racial Equity. The Ecosystem reflects a racial equity frame because one of the key goals of Nurture NJ is the attainment of racial equity in birth outcomes. All actions, decisions, policies, and interventions must emerge from a racial equity approach. It is important to understand how a racial equity frame changes the status quo approaches to maternal and infant health. It requires building new structures to facilitate power-building and preparedness for participation in decision-making in communities, and an

infrastructure to increase capacity within agencies and organizations to promote equity in all policies and procedures. The racial equity frame used considers all key contributors to racial inequities in health, and translates into revised considerations for (a) remediation of current maternal risks, (b) repair of effects of historic/past exposures, (c) restructuring to accommodate required activities, (d) removal of policies and procedures that result in disparate experiences and effects by race/ethnicity, and (e) considerations in access, quality, and delivery of care that acknowledge, respect, and accommodate the historical and current social disabilities imposed on many women because of race, income, trauma, or gender.²⁷ This action area focuses on building a statewide structure to support capacity development and structural change to support equity.

Community Engagement. Community engagement is fundamental to achieving racial equity and the other Nurture NJ outcomes and power-building is critical to the process by ensuring that communities are able to conduct critical thinking, ideation, and design among themselves before coming to a table to partner with powerful systems that usually control information and its access. This action area focuses on building a structure to support community power-building and engagement.

Ideologic Shifts. Addressing racial inequities in infant and maternal health and to make New Jersey the safest place to give birth for all women, are by far the most challenging goals because there are few good models to emulate. No drastic change—and these goals will require transformative changes—has ever occurred without some shift in the way society approaches current problems. Addressing inequities in maternal and infant health requires a different approach from addressing maternal health outcomes in general. Creating sustained improvement in maternal and infant health outcomes, and maintaining an environment that supports health over the life course requires a different way of viewing causality and of targeting intervention. In many cases, the intervention needs to be targeted toward transforming systems and the providers of care and services, in addition to those services targeted to women. Achieving success in these outcomes through the recommendations of this Strategic Plan require a change in mindset about approaches to health and to equity. This action area focuses on stimulating and supporting these mindset shifts to update thinking, systems and approaches to match the current science.

Public Policy. One goal of Nurture NJ is to ensure that the state is the safest place to have a baby. On its face, this goal may seem to be entirely the responsibility of the health care system and the policies that impact it on a daily basis. But in fact, this Strategic Plan, and the Ecosystem framework underlying it, dare us all to think much, much bigger—and imagine a system that works for every woman from the moment she is born. This approach recognizes that inequity in health is created by a multitude of factors beyond health care and, in many cases, beyond the scope of traditional public health activities. This Plan embraces a "Health Equity in All Policies" (HEIAP) approach, ²⁶ which not only considers health impacts of policy decisions, but uses an equity lens to enhance policymaking across sectors to improve the health of all communities and people. This action area focuses on identifying policies that support the contextual conditions needed for health.

Research. New Jersey-focused research is necessary to generate new information on the unique contexts of the state to inform policy and program development. Additionally, ensuring that the

generated information is disseminated to both communities and providers alike is critical—both to ensure that the information can be critically analyzed and acted upon and to generate more transparency for accountability. Innovative research is required to assess the impacts of the equity-based Ecosystem model on indicators of women's health and to ensure research funding is targeted to priority issues as identified via surveillance and data analyses. Research should also be prioritized to understand and quantify conditions that support whole person health and to develop an evidence base of strategies to remediate and repair social and historical risks and to inform public policymaking and health. This action area focuses on developing and decolonizing data collection, analysis and dissemination with information systems and processes that support accountability.

Institutional and Structural Change. Attaining and sustaining reductions in maternal morbidity and mortality, and achieving racial equity, are not outcomes that can be achieved without disrupting existing systems and ways of doing. This path will necessarily look different from anything and any ways others have traversed before. It is impossible to continue to do things the same way and expect different results. To be serious and committed to reducing infant and maternal morbidity and mortality, to eliminating racial disparities, and to making New Jersey the safest place to give birth, requires building institutional capacity that supports racial equity, community engagement, multisector collaboration, and quality improvement. Adding these actions requires structural change within existing institutions that is adequate to support these activities. This action area focuses on the types of institutional and system transformations that are necessary to hold these new approaches to health.

Social Determinants of Health. While the third column in the ecosystem represents building permanent social supports and conditions in each community across the life course, this action area represents the remediating or safety net supports needed in an immediate sense to access the indicated health and social services. This action area ensures that these services are available in each life course period so that women can access and benefit from the existing services therein.

Individual-level Care. The major focus of the current approach to health is on individual behavioral change and care. *This action area focuses on the actions that can enhance the delivery of effective individual-level care.*

The topmost action areas have greater impact on populations compared to these at the bottom. This relative positioning does not diminish the importance of any factor, as they are all critical domains of action. The action areas have different foci in each of the columns. These are described briefly below.

To achieve the goal of <u>Healthy Women</u> as the first step toward achieving improved maternal and infant morbidity and mortality and equity, the following conditions must be in place:

- Mind Shifts: Promote shift in ideology away from emphasis on women's health only during pregnancy to a fully realized whole-life approach to health
- **Public Policy:** All public policy decision-making meets health equity in all policies (HEIAP) standards and adopts an intersectional design and implementation frame

- **Research:** Develop, fund, and implement innovative and community-grounded research designs to assess the impacts of the equity-based Ecosystem model on indicators of women's health
- **Institutional Change:** Develop a process including standards, technical assistance, and designation review for all agencies, organizations, and businesses to obtain an "equity-integrated" designation
- **Social Determinants of Health:** Ensure stress-free access to resources and conditions for women to follow through on care plans and recommendations for attaining and maintaining health
- Individual Intervention and Care: Sequentially expand the coverage period and payment strategies to make women's preventive health care available equitably to all women

To achieve the goal of <u>Equitable Service and Care</u> as the next step toward achieving improved maternal and infant morbidity and mortality and equity, the following conditions must be in place:

- Mind Shifts: Attain the highest possible standard of health and safety for all women, giving special attention to those with greatest risk of poor health due to social and historic factors
- **Public Policy:** Actively seek to achieve Health equity in all sector policies (HEIAP) and consider the intersecting conditions that disable women from full participation in policy and programs.
- **Research:** Research includes QI, monitoring, evaluation, and implementation science. Funding should be directed to priority issues identified via data analysis and community-grounded needs.
- **Institutional Change:** Capacity development is structured to support all agencies and stakeholders to provide respectful care, become designated equity-integrated organizations, and all organizations are structured to integrate multisector and community engagement.
- **Social Determinants of Health:** Ensure stress free access to resources and conditions to access and benefit from services during the prenatal period
- Individual Intervention and Care: Social and preventive factors are routinely identified,
 compassionately addressed, and follow-up is coordinated seamlessly with community supports; and
 QI is conducted with an equity lens

To achieve the goal of <u>Supportive Environments and Contexts</u> as the final step toward achieving improved maternal and infant morbidity and mortality and equity, the following conditions must be in place:

- Mind Shifts: Shift policy, intervention, and funding ideology from individual-level to population-level and to building holistic, community-based solutions
- Public Policy: Systematically shift policy, intervention, and funding emphasis from individual-level to population-level solutions
- Research: Conduct community-grounded research to understand and quantify conditions that support whole-person health and to develop an evidence base of strategies to remediate and repair social and historical risks, and to inform public policymaking and health care
- **Institutional Change:** All agencies and public and private organizations obtain technical assistance to become and maintain status as designated "equity-integrated" institutions
- Social Determinants of Health: Ensure access to resources and conditions to attain and maintain health in environments where people live, work, play, study, worship, and seek help

• Individual Intervention and Care: Take advantage of opportunities for community learning, critical analysis, and expanded civic engagement.

Using the Ecosystem Map

If one were to drive to Canada from the lower US, they would need to drive north. Along the way, they would look for road signs and checkpoints to ensure that they haven't veered too far east, or west, or turned back south. That way, steady progress can be made along the way to the goal. The Ecosystem Map serves an analogous purpose toward reaching the goals of Nurture NJ: it is a map against which to monitor all activities to ensure that it leads toward building the vision of Nurture NJ. In this vein, all decisions, activity, and planning regarding maternal and child health should be first vetted against the Ecosystem to measure its relevance to achieving the Nurture NJ outcomes. This means that every opportunity to build the Ecosystem in every community should be taken advantage of—every new program, policy, funding decision, etc., should be vetted against its contribution to building the MCH Ecosystem. Emergent opportunities for funding that may not fit can be modified/adapted to increase its relevancy to Nurture NJ. This increases the likelihood of continual progress toward developing the contexts that support health equitably for all women. The Ecosystem will also suggest priorities that can be pursued in reference to emergent grant opportunities. Having a ready-made priority map and vetted recommendations can make New Jersey applicants very competitive in national or philanthropic requests.

The second use of the Ecosystem is as a blueprint for building a *place-based model* of the full Ecosystem in communities. The built Ecosystem is a long-term endeavor and the Ecosystem Map serves as a way to maintain the focus across many stakeholders over long periods of time and across many potential political regimes. It can focus community and stakeholder efforts at systems and institutional change, can extend stakeholder action to upstream points—moving beyond individual behavior to improving the communities' options for healthy choices for food, housing, employment, transportation, exercise, etc., and can ensure that multiple stakeholders across sectors can find a role in building the vision. (See Hogan, Lee and Rowley, The Built Ecosystem: Creating A Place-Based Maternal and Infant Health Demonstration for Nurture NJ, p.105 in this document.)

Finally, the Ecosystem Map can be used as an evaluation and monitoring tool. It can aid evaluation by monitoring where change is occurring among the various domains in the Ecosystem, and assess the likelihood of impact on the overall maternal and infant health and equity outcomes. Progress concentrated in only one area is not expected to achieve *sustained* improvements in maternal morbidity, mortality, or equity; activity and progress needs to be sustained across multiple domains of the Ecosystem and across multiple systems before the outcomes are likely to be achieved.

Conclusion

An Ecosystem map is seen as a critical component to making the strategic plan a viable, actionable plan for New Jersey. Embracing a shared vision, identifying shared values, and using data to guide how

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priorities are determined and stakeholders encourage and hold each other accountable as they work collaboratively to enact a new reality. Working from the same playbook will support New Jersey stakeholders' ability to ensure that the Nurture NJ vision becomes a reality that New Jersey become the safest place in the country to give birth for all.

Section II.2. The Built Ecosystem: Creating A Place-Based Maternal and Infant Health Demonstration for Nurture NJ

Vijaya K. Hogan, Elizabeth S. Lee, & Diane L. Rowley

Summary. Many approaches to health focus primarily on behavior change as a strategy and do not attend to the broader conditions affecting health. Contrary to popular belief, *individual behavior* is at the tail end of a long line of inter-dependent and determinant factors affecting health. Some communities are structured to provide most of the positive conditions needed to promote and protect health. However, for many communities in New Jersey, historical and current policies have resulted in conditions which either limit the choices for healthy behaviors among the residents of these communities, or make it much more stressful, expensive, and time-consuming to access the spaces where these health producing conditions exist. The types of communities characterized by a lack of health-supporting resources and conditions are often disenfranchised communities and disproportionately affect low income, Black or Latino communities. Therefore, this Plan proposes building a place-based model in several high-need communities in New Jersey to demonstrate the positive health and equity impacts of a built MCH Ecosystem. These place-based models can provide guidance towards ensuring all communities in the state have access to this built Ecosystem and can accelerate achievement of the Nurture NJ outcomes.

Introduction. The health of an individual or a community is a function of several factors. Each individual is encircled by these factors, and decisions—such as for health—are highly dependent on the opportunities and deficits these factors impose (refer to Figure 1). Some of the factors which lie upstream from the individual include: effects of current and historic discriminatory policies and practices (e.g., disenfranchisement), conditions of the physical environment (e.g., lead in drinking water), economic inequities (e.g., impeded access to training for existing jobs), and quality of interpersonal treatment in services (e.g., disrespectful treatment), to name a few.



Figure 1. The Social Ecological Model.

The factors beyond individual choice are often called "upstream factors" because they operate at a level that surrounds and shapes the choices available to groups of individuals within communities. The

further upstream above the level of the individual, the less individual choice is involved, and the more the individual is subjected to decisions made by others. For example; community divestment and middle class flight are actions that were not chosen by the residents who remained in divested communities, but are actions that resulted from larger policy decisions (redlining, job movement to suburban areas, etc.). Further, inaction in the face of need and thus failure to remedy the effects of disinvestment of many urban New Jersey communities is also governed by policies and decisions at upstream levels and is not fully under individual control.

Despite these two realities in New Jersey with different levels of resources available in each, there remains an overarching expectation that women should adhere to specific behaviors defined as health producing, without concurrently tending to the conditions and the historically created deficits that limit families' opportunities to adhere to healthy behaviors. Placing the onus on individuals without addressing the broader conditions surrounding them is nothing short of public health malpractice. To provide an analogy, the prevailing view in the US is that it is unacceptable to expect people with physical disabilities to "find their own way" to access health care, education or social services in buildings that do not have structural accommodations to their disabilities. Buildings are designed with accommodations like curb cuts and ramps to ensure that those with the greatest physical disabilities are able to gain access. Likewise, the recommendation to adopt a healthy diet, with the knowledge that some communities do not have markets that sell produce, and some communities do not have transportation options to get to the nearest market, creates a de facto segregated system which privileges some and disadvantages others. The objectives of Nurture NJ are to create safety and the conditions that support health to be made available equitably for all women.

To achieve the objectives of Nurture NJ, all efforts at *remediation* (advice, education, resource guides) must always be paired with actions to *restructure* women's access to community conditions that will *always support, and never inhibit* healthy behavioral choices. The roadmap for what needs to be restructured to achieve health is codified in the Nurture NJ Ecosystem map. Every community needs to take measure of its landscape and resources against the Ecosystem, and then resolve to build what is missing and improve what is lacking until every member of the community achieves equity in all the conditions needed for health.

Sample stories from Nurture NJ Community Dialogues:

"I started my prenatal care late because, (despite trying to get into care as soon as I found out I was pregnant) they could not give me an appointment for earlier than 3 months out. And I am the one who will be blamed for getting late care. There are so few service providers in my local area, and the further out clinic in the white neighborhood won't accept Medicaid, so that is not an option for me....."

"Because there are so many women on Medicaid in my neighborhood, the local clinic operates more like a factory to make sure that they get you in and out as fast as possible and that they can see as many women as possible to make their dollar. This probably explains why the quality of care is so disrespectful and usually a waste of time...."

"My Nutritionist prescribed a specific diet for my high blood pressure. There is not a single supermarket in Atlantic City, I have no personal transportation, there are no bus routes that get me to one in the suburbs, so I have to rely on substandard food in corner store"

"I do not understand why a burger costs \$1 and a salad is \$7. If I want to eat healthy like they tell me to, why is it more expensive to do so?"

Several research studies have shown that conditions of "Place", "neighborhoods", "community" profoundly affect health.³ A neighborhood that supports health and provides options for healthy behavior would include for all residents at minimum:

- A safe place to live for all residents, with protection from the elements
- An environment free of toxins and pollutants, like lead in water or mold in households
- A safe, accessible, and affordable place to exercise
- Access to a variety of affordable and healthy foods and the ability to prepare them
- Safe and affordable transportation options to access services and care
- Good quality schools
- Equal and fair protection under the law for all citizens
- Respectful and quality treatment from health and other service providers
- Access to employment providing a living wage
- Access to safe and affordable supportive services (e.g., childcare) to facilitate work or education

"To have better educational outcomes in a community, we need better schools, to have communities with incomes they can live and thrive on, requires access to viable economic opportunities..."

Source: Federal Reserve of San Francisco (August 2012)

It is widely known that income shapes access to these conditions, and for people with resources this access translates into better health. Life expectancy is longer as income increases, and economic hardship is highly correlated with poor health.

In addition, practices such as redlining, discrimination in access to loans, higher rates of arrest and conviction with no redress, and differential quality of care all affect the pathways to income generation and wealth building. These have historically been disproportionately imposed on Black Americans creating an unlevel playing field, and systems have been structured to maintain the disadvantage, even after the offending policy has been removed. Even when African Americans have been able to successfully overcome these oppressions and obtain a quality of life that supports health, it is not without a cost. Higher rates of stress are the payment exacted for overcoming these hardships, and stress is a major factor underlying or exacerbating many illnesses, including some underlying causes of maternal and infant mortality.

Segregation, structural racism, and stress infuse and transmit disadvantage through communities and across generations by systematically neglecting to endorse policies and practices that endow these

neighborhoods and communities with supportive resources, by systematically stripping the rights of people in these communities, and by erecting invisible but apartheid-like walls made up of adverse narratives, scary stories, and blame that "otherizes" people who live in the neglected communities, keeping them, and by extension—all people who look like them—on the periphery of opportunity and power.⁴⁻¹⁵

Allegory on history, lack of repair and inequitable playing fields

There was once a town called Anyville. In the early settlement of Anyville, a relay marathon race was instituted to determine resident's position in society and the resources that went along with this. During the marathon, when one generation made it to a certain point, they would pass the baton to the next generation and the next generation would begin the race where the last left off. However, in Anyville, two groups of people were socially constructed by those who were in leadership. One group was able to run the marathon unencumbered, while the other group was required to carry a 50 pound bundle on their back and shackles on their feet. Needless to say, the unencumbered group was always ahead and thus established their societal positionality and privilege, and then passed this on to their progeny. The other group was consistently behind because of the burdens they carried and as a result, were consistently blamed for being lazy, slow and unworthy of the privileges enjoyed by those who were ahead in the race. After generations passed, people began to protest the unfair burdens the one group was saddled with. After a time, they were able to garner the political will to end this requirement and off came the weights and the shackles. Everyone rejoiced and celebrated the new freedom of this once- burdened group of people. However, their societal positionality based on the historical burden was never addressed, and when they continued in the marathon, they still lagged far behind the privileged class. Because most in that group remained behind despite their freedom from the burden, the narrative that they were "just inherently unworthy" grew even stronger in the population. Even when some of the previously burdened group were able to overcome their historic deficits and, at great costs caught up to the privileged class, they were still excluded from privilege because they were already marked with the same narrative that covered the rest of their group. Life for this group continued as if the burden had never actually been lifted.

Abbreviated History of Place-based Intervention. Knowledge of the impacts of neighborhoods /place on health is not new. In fact, the field of public health is built upon the notion that health of populations is affected by the organization and contexts of their social and structural environments. Just as knowledge of the impact of Place on health is not new, neither is the knowledge of the positive and profound impacts that place- based *intervention* has had in communities.¹⁶

Case History: John Snow, Cholera, and the Broad Street Pump. A wave of cholera first hit England in late 1831. Twenty-three years later, medical knowledge about the disease had barely changed, though one physician, Dr John Snow, a pioneer of the science of epidemiology, speculated that it was spread by contaminated water — an idea with which neither the authorities nor the rest of the medical establishment believed. Whenever cholera broke out — which it did four times between 1831 and 1854 — nothing whatsoever was done to contain it, and it rampaged through the industrial cities of England, leaving tens of

thousands dead in its wake. The year 1853 saw outbreaks in Newcastle and Gateshead as well as in London, where a total of 10,675 people died of the disease. In the 1854 London epidemic the worst-hit areas at first were Southwark and Lambeth. Dr Snow took a sample of water from the {main} pump to the neighborhood, which was on Broad St. On examining the water from the pump under a microscope, he found that it contained "white, flocculent particles." He was convinced that these were the source of infection, and he took his findings to the Board of Guardians of St James's Parish, in whose parish the pump fell. Though they were reluctant to believe him, they agreed to remove the pump handle (to stop the flow of contaminated water) as an experiment. When they did so, the spread of cholera dramatically stopped.¹⁸

Changing the conditions affecting whole communities has long provided more rapid and dramatic impacts on health compared to a sole focus on treating or educating individuals.

The US also has a long history of place-based intervention to improve health, beginning with settlement houses. These earliest models were charity-based models located in high-need communities, providing resources, education, care, and support where there were no other services. In addition to charity care, these models also participated in advocacy to affect the public policies that could improve conditions and opportunities in these communities. In the 1960's and '70's, community organizing movements, such as the Black Panther Party, initiated place-based services such as free breakfast programs, and health clinics in Black communities.

Case History: The Black Panther Party launched more than 35 Survival Programs and provided community help, such as education, tuberculosis testing, legal aid, transportation assistance, ambulance service, and the manufacture and distribution of free shoes to poor people. Of particular note was the Free Breakfast for Children Program (begun in January 1969) that spread to every major American city with a Black Panther Party chapter. The federal government had introduced a similar pilot program in 1966 but, arguably in response to the Panthers' initiative, extended the program and then made it permanent in 1975. ¹⁹

The free School Breakfast and WIC programs were modeled on this community-based program, and the War on Poverty, community health centers, and other social safety net programs emerged from these community-led, place-based efforts.

What exactly is a "Place-based Intervention"?

Place-based approaches emerged because of the recognition that the problems individual people face, for example health—exist for whole communities and thus it is more efficient to define a community solution rather than leave each individual to hatch a solution. Also, communities rarely face discreet problems, but intersecting, interdependent, and sector-spanning challenges. Addressing a discreet problem in one system can destabilize a family's relationship to another system.

A place-based intervention is defined as a process of focusing resources and action toward a defined geographic area in order to improve conditions and outcomes in the area. The goal is to address many intersecting challenges through a more holistic approach, negating a need for tradeoffs between priority needs. However, place-based strategies have been variously applied —from placing a specific

intervention, e.g., a diabetes education program—located within a high need community, to the development of a multifaceted community empowerment zone that is focused on overall community development. In fact, place-based approaches can be typed on a spectrum:



The more impactful and sustainable place-based intervention, on the far right-hand side of the spectrum, is the goal.

In essence, the complex challenges posed by neglected communities cannot be solved by one agency acting via a siloed approach and are nearly impossible to be solved by an individual on their own. The complexity of intersecting problems requires a holistic, comprehensive, multifaceted, and collaborative strategy to structurally build access to all of the necessary resources and conditions for health and well-being in every community.

What are the characteristics of an effective Place Based Intervention?

What does a good place-based approach entail? Not all place-based work has proven successful. Just like any other community change approach, the way a place-based intervention is implemented will determine its success or failure. There are a number of reviews of place-based models that help to paint a picture of what contributes to their successful implementation.

Assuming a place-based model to be "a long term, multi-faceted collaboration to achieve broad social and community change", reviews of place-based models provide clues to the characteristics that make them successful. Some of the key characteristics include:

- Granular knowledge of the landscape and history of the community.⁴ This knowledge is necessary to
 ensure that adverse effects on people in a community are minimized and benefits are maximized,
 and requires authentic and deep community engagement and power sharing to accomplish.
- Efforts are planned and implemented with community partnership and communities co-own the process.
- Interventions are holistic and are comprised of long-term investment, rather than being programs that target a specific intervention.
- Since economic marginalization drives most problems in disenfranchised communities, ensuring a linkage of the community into a larger regional economy is necessary to leverage market forces to drive local change.
- Employ multiple sector involvement and collaboration.
- Efforts build in adequate start up time for planning, learning, and relationship building.
- Enjoy leadership and support from all levels of socio-ecological model.

- Employ an equity frame so as not to exacerbate ill effects, such as residential displacement and homelessness via gentrification.
- Rely on private sector as well as public sector and philanthropic funds to ensure stakeholder participation in generating community benefit.
- Non-health entities are clear about the impacts of their sector on health and vice-versa.
- Backbone organization leads and provides monitoring and oversight.
- All stakeholders share a common vision for community development.

These characteristics can serve as a checklist for implementing an effective place-based model.

What is the Process for a Place-based MCH Model in New Jersey?: Building the MCH Ecosystem A place-based model for Nurture NJ would need to be based on an equity framework and include focused efforts begin to achieve the contextual changes in community needed to support maternal and infant health. The place-based approach would include using the ecosystem as the blueprint for community change. The ecosystem contains the components that need to exist to support healthy communities, healthy behaviors, respectful and effective clinical practice, and equitable outcomes, and represents the vision of what needs to exist in every community for every woman to attain health and have safe and healthy pregnancy outcomes.

For development of the Nurture NJ place-based models, the following process is recommended:

- 1. Use geographic mapping to identify priority hot spots in the state.
- 2. Solicit proposals for 1.5 year planning grants in each of the regions to support development of collaborations, planning, and learning for the place-based, collective impact effort.
- 3. Set requirements for planning grants: for example, require the stakeholders that must be engaged in each collaborative, to include:
 - Community
 - Private sector
 - Regional economic drivers
 - State agencies
 - Philanthropy

Other requirements should include a high level of community partnership, ownership, and power sharing; selection of a backbone coordinating organization; specific and sound processes outlined for relationship-building, level setting, learning, vision-setting, and planning.

4. Choosing a starting place. Under the assumption of limited resources, after the planning period, a new RFP would solicit implementation proposals from the planning grantees. One to four communities in the state should be selected and funds provided to implement the first models of the built MCH Ecosystem. For New Jersey, the ideal would be to start with a minimum of three implementation models, including one in North Jersey, one in Trenton, and one in South Jersey. Private sector business and philanthropies should be organized into funding groups to supplement

public funding of these models. If adequate funding is not available initially to fund three implementation models, a selection criterion could be based on either priority need based on highest rates, priority based on number of births, or on the likelihood of success in building the model. Model sites would serve to provide technical support to other areas seeking to build /implement components of the ecosystem. Lower levels of funding can be provided to other sites to continue their development and competitiveness for future funding opportunities.

5. Providing Resources and technical assistance to sites not initially funded. A tiered funding approach is recommended to ensure that all sites have resources to maintain and continue their partnership building, learning, design collaboration, and structural changes in anticipation of future funding as resources become available.

Timelines, Resources and Policy Supports Needed

Timeline. The planning grants should be for at minimum, 1.5 years or up to two years. Implementation grants should be a long term (5-10 year) investment with accountability structures for process achievements built into funding renewals.

Policy supports needed. Local models will require policy action and supports at the state level to successfully build the MCH ecosystem. These are detailed in the Nurture NJ Strategic Plan Nine Action Areas.

Conclusion. All women, children, and families in New Jersey must have full access to the range of policies, resources, environments, services, and care across all sectors of society that create and sustain health. This means, they must have access to good care, but also have access to the social determinants of health (food, housing, transportation, jobs etc.) to create the conditions that promote, support, and sustain health.

The Nurture NJ Ecosystem Map was designed to provide a common vision and blueprint for multiple agencies, stakeholders, and sectors to do what they do best, both together and separately, to systematically contribute toward building these conditions for health in a community.

Nurture NJ recommends building a demonstration of the full Ecosystem in high need places in order to work out best practices for how it can best be accomplished, to provide a best practice model to guide other communities in the state to create their built ecosystem, and to demonstrate the positive impacts on health that having access to the full complement of conditions for health can achieve.

A built ecosystem for maternal and infant health in targeted communities using the state-of-the science approaches as outlined here, and targeted to specific communities in New Jersey can accelerate the unfolding of positive maternal health, and infant health outcomes and well-being that will make New Jersey the safest place to give birth.

Section II.3. Building Infrastructure to Support, Promote and Maintain Racial Equity and Community Power-Sharing in all Policies and Processes of Nurture NJ

Vijaya K. Hogan

Racism finds its way into all systems affecting the health of women and children—including health, social services, criminal justice systems, housing, food systems, employment, etc. For Nurture NJ to be successful in achieving equity in maternal and infant outcomes and in making New Jersey the safest place to give birth, some hard work is needed to dismantle the systems that hold racism in place.

What does it take to dismantle racism? The strongest tool the US has to protect against inequitable treatment is legislation. This is why it is important for the highest levels of government to set the standard. However, legislation does not always translate into execution when the public has not been brought along with the changing laws and culture. For example, in 2015, same-sex marriage was legalized in Kentucky. The then county clerk for Rowan County, KY, refused to follow the Federal court's ruling because she had a religious or personal objection to same-sex marriage and rejected licenses for same-sex couples (Blinder & Lewin, 2015). Even the power of the law may not be enough in and of itself to change the culture of racism and discriminatory behavior of individuals. Awareness of the inequities, the ability to see the role that policies and structures play in promoting inequitable impacts and in protecting privilege, empathy for the populations who are victimized by inequities, an acknowledgement and a commitment to fostering change by assessing and undoing inequitable policies and procedures—are all necessary, in addition to laws and policy, to create and sustain a movement toward equity. The question is—how does Nurture NJ achieve this?

What makes Nurture NJ distinct from other strategic plans is its commitment to eliminating the role that racism plays in New Jersey's rates of maternal and infant mortality. However, the success of Nurture NJ depends on systematically dismantling the systems that hold racism in place. This in turn, requires a careful navigation through defined stages of equity capacity development and creating the necessary conditions for transformation of systems and structures into equity promoting entities.

Nurture NJ recommends the development of a structured approach to building the capacity of all stakeholders and citizens in New Jersey to be able to: (1) assess their own level of capacity for promoting equity, (2) assess the existence of racism in structures, policies, procedures, and actions in their realms of influence, and (3) operationalize their equity capacity to collectively dismantle these systems and replace them with equitable ones. The structured approach must be a statewide one to create a culture of health equity—where all stakeholders work together to achieve these capacities and act upon them. Just as the country learned to "shelter in place" and "social distance" in the face of COVID-19, communities must also develop a new capacity to recognize and address inequities in daily life. The Nurture NJ Strategic Plan defines the steps to accomplish this.

Plan to Build Equity Capacity for All of New Jersey. The following outlines the basic recommendations for making New Jersey the first state to intentionally build a statewide structure to achieve the highest level of racial equity capacity.

1. Develop a state legislative commitment to ending racism and declaring racial disparities a public health emergency (see: Strategic Plan recommendation 1.2).

In only the past year, at least three counties in US states have made formal declarations of racism as a public health emergency. The Milwaukee declaration (May 2019) was formulated to ensure that racism is a part of public discourse and that it plays a role in decision-making processes including in health, housing, economic stability, etc. The resolution requires assessment of all public internal procedures and an increase in diversity and inclusion. The Franklin County, Ohio Council (Columbus, OH) declaration states that racism is a pandemic that existed long before COVID-19 and must be addressed. Allegheny County in Pennsylvania's declaration (Pittsburgh) stated that addressing racism is a humanity issue rather than a "black" issue (see Nurture NJ Resources for examples of anti-racism declarations). In addition to the declaration, they established an investment fund and leadership forum to ensure elimination of barriers and inequities.

New Jersey is not exempt from the experience of inequalities—either for women or for people of color. The level of disparities in maternal mortality and infant mortality, and the underlying contributors to these outcomes, serve as indicators of the differential experiences by race visible to all. The experience of racism is not new in New Jersey, and community dialogues with women in the state revealed that the experience of racism is pervasive. As discussed earlier in this plan, racism has many forms and can be intentional or unintentional. Racism and its adverse impacts on health will not end on their own but require an intentional and structured process to dismantle racism in its many forms.

In order to break the cycle and dismantle the structural and institutional manifestations of racism in New Jersey, the Strategic Plan includes a recommendation for New Jersey to make a declaration of racism and racial disparities as public health emergencies to elevate the importance of this issue and give it the full weight of government support.

2. "Not about us without us." The state and the private sector make a commitment to structuring community engagement in decision-making, design, planning and implementation of programs and policies affecting communities (see: Strategic Plan Recommendation 2.2).

The use of community engagement has become considerably more common in the public health arena in the past decade and is often required as a prerequisite to many state, federal, and some private sector grants. However, community dialogues in New Jersey revealed that many women feel they are not appropriately represented, or, when represented, not fully heard in these decision-making processes. The challenges of inadequate representation arise from several structural limitations: (a) community voice is brought in too late in the process when it is impossible to make requested design changes, (b) not enough funding is allocated, thus forcing choices among competing priorities and creating, at best, partial solutions, and (c) there is little organizational commitment to actually

embracing innovation, which is required for impact on health inequities. All these challenges originate with the lack of a permanent structure within public health and medical facilities to share power and integrate community voice authentically in decision-making processes. The Nurture NJ Strategic Plan therefore proposes the development of a permanent structure that elevates, supports and sustains the ability of all state agencies to integrate community engagement permanently in all decisions relating to information generation and sharing, planning, collaboration, learning design, and evaluation.

State and private sector funding is needed to support democratization of health-related decision-making by building civic engagement and community learning structures. Community engagement, like all the components of this Strategic Plan, must be implemented authentically with fidelity to principles of democracy, humanity, social justice, and science, and not just as another requirement to be done as minimally as possible, and then ticked off a list. This type of civic engagement is particularly important since dissatisfaction with democracy is increasing: ..." fifty-five percent of Americans say that their democracy is "weak," and 68 percent fear it is getting weaker. Roughly half agree that America is in "real danger of becoming a nondemocratic, authoritarian country." Further, many believe the system is rigged: Some 70 percent of Americans say that "Our political system seems to only be working for the insiders with money and power" (Henderson, 2020). The situation is even worse among young people aged 18-29 who report they have "more fear than hope about the future of democracy in America." This increases the imperative for intentionally structuring support for civic engagement to bring the voices of people back into the decision-making processes affecting them.

The major strategy for implementing community engagement in decision-making, if conducted at all, involves bringing community members or representatives to the table, often after the major decisions are already made. In these cases, community representatives are at a disadvantage because they have not had an opportunity to convene with their fellow residents, to learn, discuss, process, critically analyze, and design possible solutions that have fidelity to the life, history and culture, and intersectional needs of the community. Instead, the community representatives, often outnumbered at the table by institutional representatives and experts, are expected to provide adequate thought partnership. The level of thought partnership is often limited to tinkering at the edges of the organizational plans because the community has little opportunity to internally process information about themselves generated by public health organizations. There is little access to public health data in the community, community members provide counsel, but rarely see the manifestation of that counsel, and the information that communities are made privy to is carefully curated by the initiating organization. Colonized knowledge, defined as limiting knowledge generation to the sole interpretation and worldview of those in power, is a key structural pathway for maintaining inequities. To decolonize the knowledge generation process which shapes all subsequent activity, structured community dialogues, allowing community an opportunity to process information as a group, before coming to the table, is a necessary tool of democracy, and governments have a responsibility to ensure that people in communities have a structure to do this.²⁵ Therefore, for Nurture NJ, public and private partnerships should be organized to fund the development of ongoing community structures for critical analysis, idea generation and design of solutions affecting their own community (see: Strategic Plan recommendation

- 2.1). It is only after this that community members will be able to appropriately represent all members of their community at the decision-making tables.
- 3. Utilize an Equity assessment and stages of change frame to attain a high-level capacity to promote equity in all policies across the state of New Jersey.

Equity in maternal health exists when you cannot predict a difference in morbidity and mortality by race/ethnicity. Equity is achieved through a process that includes the elimination of racism in current policies, practices, attitudes, and cultural messages—those that measurably disadvantage some population groups relative to others. Achieving equity also includes correcting the damage inflicted through past policies, practices, attitudes, and cultural messages that have positioned some population groups on an unlevel playing field. The skill to conduct these activities is not inherent and therefore must be learned. This recommendation focuses on the need to significantly and systematically increase the capacity to promote equity in all sectors in New Jersey. There are stages of development to a highlevel equity capacity. Currently, there is no systematic way to obtain equity capacity or to determine what training is appropriate for whom. Often, learners in equity trainings leave with a negative opinion of the training, quite possibly because they were participating in a level of training that was beyond their level of readiness. As an example, implicit bias training has become very popular in the public health arena as a way to impart equity skill. However, under the stages of change model, implicit bias may not appropriately take hold and result in actual sustained manifestation of transformed action because the prior stages of change were not developed thus there does not exist a strong basis on which to build the learnings of implicit bias training. New Jersey should adopt a stage of change model and require and conduct assessment of all agencies and personnel to determine their stage of readiness. Capacity building, technical assistance, and resources can then be more effectively targeted with a stronger impact. The implicit bias training, already legislated as a requirement for state health personnel, should be structured to ensure achievement of all pre-requisite levels of equity capacity.

4. A state and private sector-funded structure for statewide training and technical assistance (TA) for state agency personnel and other stakeholders to obtain the highest level of capacity to conduct personal, institutional and structural assessments, and transformative action to support and maintain equity (see: Strategic Plan Recommendation 1.1).

In order to operationalize the capacity building discussed above, state leaders should develop an infrastructure for learning. The training capacity can be jointly funded by public and private entities and should maintain the ability to provide technical assistance and training at all levels of readiness and to assist agencies in attaining designation at the highest levels of equity capacity. When all staff in all agencies are acting through an equity frame in all actions and decisions, the impacts on population health will be dramatic.

5. All stakeholders make commitments to incorporate equity capacity development into personnel procedures (see: Strategic Plan Recommendation 1.1, 1.6).

The capacity to promote equity in all policies should be a feature of all public and private sector entities alike. All sectors in New Jersey should take part in the capacity building to achieve the highest levels of equity capacity.

6. All organizations and institutions in New Jersey make a commitment to achieve the highest designation as equity proficient organizations (see: Strategic Plan Recommendation 1.5).

A designating body should be stood up in New Jersey to oversee the development of a capacity building structure and to oversee the assessment and designation process. Having a designation process with an entity that can lead the capacity building efforts and an independent body to conduct designation reviews will allow transparency to the public on the level of equity capacity in each organization. It will also serve as a motivation for agencies and private entities to traverse the pathway to the highest levels of equity capacity. At the highest levels of equity, agencies and the stakeholders within them are actively and intentionally assessing and dismantling systems that promote inequities and replacing them with more equitable processes. This can be modeled using the Baby-Friendly designation process as a guide.

II.4 Best Practices: Racial Equity and Racial Healing Initiatives

Luz E. Benitez Delgado & Elizabeth S. Lee

In order to achieve the vision of Nurture NJ, all communities and all sectors must be engaged in racial equity awareness, practices, and processes. During the Nurture NJ strategic planning process, the most common thread in community conversations on health outcomes for women and their babies were *lack of respect and racism*. New Jersey needs to heal first from the harm done in order to move forward. Acknowledgment of past histories is part of the respect owed to the community of women who may or may not understand why this is happening to them. Not until this trust-building is developed, and power-building within their community emerges, can communities in New Jersey move forward with new systems and ways of serving.

In order to provide motivation for this within sectors and at individual levels, and manage the mind shifts that are required for Nurture NJ goals to appropriately unfold, The Truth, Racial Healing and Transformation (TRHT) process can serve as a useful model. The TRHT was first applied at the national level and is now being replicated in 14 regions. It is transformational in nature rather than transactional, such as you would find in a project or initiative. It intentionally touches the heart to move the minds of decision-makers and community forward with a purpose for racial equity. Continuous practices and processes which assure a community honors racial equity in all their decision-making to support their common humanity and successful outcomes for everyone is planned and nurtured by all sectors. What follows is a summary of best practices from these processes as they have been carried out across the US.

Healing Circle Conversations. To start, a platform using healing circle conversations sets the right stage with experienced healing practitioners for trust-building and ideation of what racial equity would look like in their respective regions. This process is currently taking place in select sectors in 14 regions in the US based on the desired changes community members and corresponding sectors agree upon. The most commonly identified areas for racial equity transformation are the economic gap, access to quality education, policy changes relating to collateral consequences, access to quality health care, and the criminal justice system, among others. Once communities of leaders come together in each respective area of interest to heal, honor the harms done in the past, and create a vision for the future they desire, these leaders unite to identify community and sector leaders, and ways to create the desired racial equity framework in their region. The shared humanity unveiled in healing conversations is the glue that holds the difficult conversations on racism community decisions will encounter as they design their desired future.

Specific Tactics

- Learn history and current reality of geographic location(s) selected. You will need a good historian (or entity) knowledgeable of diverse populations, racial equity indicators and process, different cultures, historical, and political contexts.
- Acknowledge harm done. Bring the science to the table and assist community in understanding systemic linkages and adverse consequences.

Case Study: In 2014, the National Parks Foundation embarked on truth-telling efforts, healing, and a more explicit plan to diversify their staff and park personnel to mirror communities in the US. With almost 57 percent of their workforce eligible for retirement at the time; in the forthcoming five years, it was an opportunity to commit wholeheartedly to diversity, equity, and inclusion by making a commitment to hire people of color for vacant positions left by retirees. It was found that children from under-resourced neighborhoods were not attending the parks, for many reasons, the greatest need being funding for transportation. The process began with informational one day session in Washington, DC on racial equity and healing. Their commitment and passion for the work to start in the Parks was immediate. The National Parks Foundation was able to gain support from the White House at the time for all 4th graders and their families to be allowed to visit the parks free of charge for the entire year.

- Community conversations and healing practices: train a cadre of healing practitioners, and community engagement advocates and facilitators.
- Create or support social or cultural events to learn about other cultures e.g., Heritage Month activities.
- Use local resources for facilitation, events, historical awareness; include business venues to support local entities and demonstrate collaborative good will.
- Conduct community and healing conversations with all sectors. Train a cadre of healing
 practitioners. Agencies and community need to engage simultaneously in their own groups, and
 when the groups feel ready, integrate them with community conversations to collectively develop
 new systems of caring and milestones to be achieved. Use data, questions, themes relative to the
 subject matter; women and their babies, as presented in the Ecosystem Evaluation,
 Communications, and Marketing plans.

Sustainability through Oversight. These processes for community engagement and healing are all overseen by an advisory team of experts (chosen by the community), both local and national, for each sector of interest. Relationships are continuously nurtured through a system of ongoing conversations, training of local community members to take charge of the TRHT framework when they feel ready (training facilitators and healing practitioners in each region or sector), and supporting them with advisory team member expertise when requested. This generative action to enter into the space of transforming structures which have historically created barriers, gaps, and disparities for underserved

communities is the walkway to dismantling historical structural racism no longer relevant in regions in the US as demographic shifts are rapidly changing the landscape of communities. The community engagement and power-building practice to strategically have a cross-section of all communities represented at all the sector tables are crucial to the success of trust-building among sectors.

Specific Tactics

- Devise different awareness-building opportunities that are culturally and linguistically relevant, and support the development of learning communities.
- Provide racial equity awareness building through various tools; online seminars, dialogues, internet,
 TV programs, Radio programs, among other master classes by a team of experts on community engagement and power-building and racial equity.
- Give visibility to community voices in the development of better outcomes. Train some as advocates
 with expertise in communications and marketing that will support the emergence of compelling
 narratives and new entrepreneurial ventures that supports the well-being of women and their
 babies.
- Develop long term opportunities for continued alliances and learning with viable and traceable outcomes and written commitments.
- Create continuous information loops for communities on needed improvements or new developments.
- Assure all voices of the community are at the table in all the sectors (advocate for new policies, standards and guidelines). Rotate participation of leaders that emerge yearly, to balance power and community engagement.

Case Studies:

1) The Greater Buffalo Dividend Report composed by a Racial Equity Roundtable of more than 30+ businesses, not-for profit organizations, and state and private economic engines, is a perfect example of how business and different alliances can contribute to a region's transformation applying racial equity principles (https://cfgb.org/wp-content/uploads/2018/08/racial-equity-dividend-report-2018.pdf).

Business Community Engagement. Transformation efforts in regions, such as New Jersey, also have the challenge of involving the private sector, non-health, and for-profit entities as partners in this vision. Influential leaders in the business sector must be identified early and be engaged in all the TRHT processes from the beginning. Trustees would be the first point of focus so as to serve as a model for their organizations where TRHT efforts would trickle down to all individuals in their organizations, including being reflected in their policies, practices, benefits and guidelines.

As business is part of the engagement strategy of the TRHT, it should also go through the same process of awareness-building, trust-building, and ideation through healing circles and generative conversations, beginning with their decision-makers such as trustees, the C-suite, Boards or regional associations such as Chambers, federations, alliances, among others. In some cases, TRHTs used a Business Case for Racial Equity to incite interest of the private sector. This is an analysis of the costs to the economy of maintaining racial inequities.

Case Study: The TRHT in Los Angeles is a new multi-faceted partnership with business, community partners, nonprofits, government and partnerships with philanthropy. This non-partisan and collaborative partnership was coordinated by the Southern California Grantmakers Association. The TRHT process in LA has a strong commitment to transform their city, including the Mayor's office. Among other examples, this is evidenced by their advocating and influencing decision-makers to use a racial equity lens in the appointment of a new police chief, to the appointment of the new superintendent for the New Unified School District. Both points of influence included suggesting an engaging process of conversations that sustain racial equity in Los Angeles.

A business case can quantify the benefits of: Intentionally built systems for people of color to earn wages equal to their white counterparts, addressing gaps in health disparities, increasing graduation rates, among other efforts, which would level the playing field in several sectors and contribute to potential economic growth in the US. With global intersectionality more evident, world economies cannot continue ignoring lost potential of their populations. Inequities caused by lack of resources and opportunities are evidence of poor economic planning for any business or region in our current context of diverse and multilingual populations. This blindfold costs billions of dollars in lost opportunities for economic success.

Current business case analyses indicate that billions in increased consumer spending power can go untapped if the US is not prepared for current and future shifting demographics. Including all populations in the economic growth of the country can realize \$1 trillion in higher earnings, \$800 billion in spending, and would mean an additional \$2.6 trillion by closing the earnings gap by 2050. With the current unemployment in the US at 14 percent due to the COVID-19 pandemic, the breakdown caused by this pandemic provides an opportunity to create more fair and inclusive economic systems using a racial equity approach to put the country back on its feet, and also ready itself for future supply and demand based on the projected growth by 2050 of communities of color.

Specific Tactics

- Have a Business Case for Racial Equity developed for New Jersey which brings forth the cost of disparities not only economically but also on human life; specifically, women and their babies.
- Conduct town halls to present to the community.

- Present private and sector conferences or panel discussions on racial equity to continue nurturing learning communities for racial equity and increasing power-building activism which supports an emergence of compelling narratives.
- It is important that communications and marketing professionals, as well as evaluation experts, accompany this process from the beginning to seize opportunities to support data and storytelling that transform perceptions and grow inspiring narratives to support movement building.

Organizational assessments. When organizations feel their diversity, equity and inclusion (DEI) efforts evidence their commitment to fairness, creating a culture of racial equity in their environment means honoring their journey to diversity, equity, and inclusion first, before evidencing their potential for racial equity. Communities, businesses, and systems need to start somewhere. Creating racial equity processes takes time for the journey to transformation to become a values-based process and not a transactional project, or initiative. Not all environments or entities respond well when you start with the tough conversation as to the historical and structural barriers which have emerged due to a history of racism. Interest can be sparked in the business sector to gain momentum for racial equity via their introduction to strategies, tactics, and learning communities, at conferences on racial equity, panel conversations, visits to successful efforts, and through training and development opportunities, not only on debiasing strategies but also on how and why eliminating barriers to success affects the well-being of entire systems, businesses, or communities. There are various assessment tools for individual and organizational growth in the arena of racial equity and inclusion, and also effective models that can accompany other learning opportunities applicable to business needs to gain strides in desired outcomes.

Dynamic, accountable leadership. Linking with other organizations to build community capacity is an opportunity better developed when there is an organizing body or person in a community that is recognized as an influential leader. For example, if we look at the TRHT in Greater Buffalo, their Community Foundation is led by an influential executive director who has been able to create a national alliance for community foundations doing diversity, racial equity, inclusion, and racial healing. Because of her leadership, she was able to bring faith-based groups, businesses, non-profits and for-profits, and policymakers to the table to explore a "common vision" for the Greater Buffalo area by creating an indicators report for their region and tracking success for racial equity and inclusion. This type of leader, plus aligning with like-minded efforts in the country, enriches ideation of new systems and replication of what's working in the field of racial equity for business and all sectors.

Specific Tactics

Coordinators in each geographic location working through a THRT process should connect back to a
main hub, allowing for flexibility and improvement of all processes and lessons learned and applied.
The main hub would have oversight of accountability to the ultimate goal to reduce infant and
women morbidity and mortality. The main hub should be the "go to" expert for New Jersey (and the
nation) on data and outcomes, and house knowledge products such as racial equity guides for

different disciplines, learning opportunities within the racial equity field, and histories of past harms done which inform current transformation.

This central hub should also be held accountable by a governing racial equity board or ombudsman
appointed by community voices and sector partners and should have individuals that mirror the
communities being served (women, men, family members, healthcare providers, legislators, pastors,
multilingual populations, etc.).

Mindset shifts. Among many important elements of a racial equity lens is creating safe spaces for generative conversations. This means creating a space for developing agreed-upon language; and glossary of terms for common understanding and the ideal shaping of narrative change efforts. This will help to create messages for communities, sectors, and businesses that are not blaming or shaming, are constructive, speaks to the audiences' main concerns, and are generative in nature for actions to be intentional and inclusive. Healing practitioners in the 14 regions practicing TRHT, and also in several national sectors, are trained to best create these safe spaces for trust-building and supporting new narratives.

Specific Tactics

- Create a yearly Racial Equity Report for New Jersey; highlighting how you are moving the needle for women and their babies.
- Create awards and recognitions for both community and systems change and publicize in ways that elevates their status in the community change desired.

Co-designing and decision-making. Community voices are essential to the ownership of collective change. Maintaining women's voices, stories, ideas, and assessing systemic change successes with their input, is essential to a stronger commitment to actively engage the community and to also reduce disparities and adopt racial equity as a way of being. All of this is possible through healing conversations and community engagement and power-building. Engaging communities and their partners and families should also be accompanied with routine engagement of all the systems that support community well-being for the targeted populations. It needs to be a sincere effort to LISTEN, engage, allow participation and disagreements as well (agree to disagree) to support a trust-building that will sustain decision-making when there are tough decisions to be made. The foundation for the desired collective impact of the desired goals must include the active and repeated reinforcement of why racial equity is a standard practice and process for New Jersey's success and reputation of excellence.

Specific Tactics

- Develop expertise within the sectors for racial equity facilitation, healing practitioners, data
 collection, policy and systems change, accountability boards, committees, etc. This will allow the
 newly gained awareness to become the process of choice in all systems; not a project or an
 initiative, but a way New Jersey maintains their standard of leadership in the field of maternal and
 infant health.
- Training local participants in the TRHT process and community engagement and power-building strategies will support sustainability and empower a community-driven effort in New Jersey, from business and across all sectors up to health care providers and institutions who unconsciously add to current disparate outcomes.
- Share resources among the community and sectors; all forms of media (films and documentaries about New Jersey's success, library, schools, journals, radio, TV, etc.) to flood all media with learning opportunities and create a culture of learning about racial equity.

This process will vary depending on the readiness of the community; for less aware communities, at a minimum, three-day sessions, three times a year. The process could be a mixture of designed and facilitated healing circles, informational forums, along with sponsoring attendance at global conferences, or panel conversations, or with the private sector having their own development and training program for staff or at recruitment. For communities with social justice and racial equity consciousness, this depends on the plans these communities come up with at their engagement opportunities. It could look like developing an oversight council, a call-in resource center, schedule for mixed cultural events, celebratory events for successes, advocating for curricula changes in schools, policy, or even a regular tool for continuous learning (library series, TV, radio, etc.). They might even advocate for major think tanks for racial equity to open offices in the geographic areas affected, or advocate for major conferences pertaining to improvement of birth outcomes to hold their conferences in New Jersey. Depending on the dynamism of the group(s), this can take from 1-2 years depending also on how large the geographic area is.

II.5. Community Engagement, Community-Building and Power-Sharing

Esther Nieves

Community Engagement

- Augment the First Lady's resource and information sharing through virtual communities, including
 multiple platforms and other communication strategies rooted in a popular education methodology
 (e.g., virtual platforms, radio ads, neighborhood leafleting). Virtual communities can come together
 using technology resources to activate a supportive learning community of practice. This technology
 recognizes the limits placed by the current pandemic as well as the ability to form sustainable
 relationships throughout New Jersey.
- 2. Pilot a "family engagement" component as a holistic approach to promote childbirth education, patient care (pre, post, and future wellness), and general health literacy. Family engagement can occur in high schools, using community groups that already have parenting and family development classes, and have "street credibility." Also, organizations that already serve a WIC population (or provide other healthy family programs) can incentivize them to participate in family health literacy, childbirth education, etc.
- 3. Bring together community trailblazers and champions who have influence, access, and exert leadership within a community or sector (e.g., corporate, civic, congregations/faith-based and community). These are individuals with access and influence who can draw the participation of others, and can commit to being part of statewide efforts to address maternal and infant health. Trailblazers are influencers, not necessarily positional leaders; they are present, respected, and engaged in their communities, and they have demonstrated a commitment to community empowerment and racial equity.
- 4. Develop a multi-prong marketing (e.g., electronic, print, social media platforms, neighborhood outreach) and information-sharing plan to engage all New Jersey stakeholders. Include informal community and sector-based networks (e.g., neighborhood clubs) and formal corporate, civic, faith-based and community leaders, health and wellness professionals, community organizations (e.g., community clinics), and grassroots partnerships working with those impacted directly by health and wellness disparities.
- 5. Establish virtual communities with organizations that receive state funds to support the implementation, monitoring, and evaluation of the recommendations outlined in this report.
- 6. Implement a focused faith-based strategy to engage congregations, ministries, missions, women's auxiliary groups, and spiritual leaders in the targeted communities. Prioritize faith sector leadership to address maternal and infant health as part of their guiding religious priorities. Consider supporting faith-based campaigns that champion maternal and infant health and wellness that resonate with spiritual teachings and values (e.g., Faith in Action for N.J.'s Mothers and Infants, Congregations for Children, etc.).
- 7. Build a public awareness, engagement, and education campaign that is multi-lingual and multi-generational to emphasize maternal health as family health.

Community-Building

- 1. Coordination with the Nurture NJ place-based effort supports a community visioning process that engages mothers, parents, families, residents, and organizations to identify the needs and the actions required to improve maternal and infant health. The process helps build self-efficacy and strengthen their confidence in the "new" health delivery approach to pregnancies and childbirth.
- 2. Build the community capacity and the skills for residents and communities to "step into leadership" with training that supports personal narratives and life experiences. These core life skills help address trauma and stress in the lives of expectant mothers, families, and community members; assess currently available culturally respectful training in use or developed by New Jersey-based organizations.
- 3. Allocate public funds and resources to provide pre-, during, and postnatal childbirth education to women and their families through partnerships with community organizations already present and working with families in underserved, under-resourced communities.
- 4. Enable existing alliances and networks to be training sites for residents and organizations to develop and hone their leadership and decision-making skills in preparation for their participation in a revamped public health approach, including in leading efforts to address maternal and infant health.
- 5. Promote health and wellness literacy in New Jersey's public-school system to support students' awareness of healthy lifestyle choices, childbirth education, and comprehensive human sexuality.
- 6. Earmark state resources to support family success centers as sites for prenatal child educators to provide multi-generational prenatal childbirth education and outreach to teen girls and young female adults.

Community Power-Sharing

- Establish the Governor's Maternal and Infant Accountability Council. The Council
 galvanizes support for and carries forward a statewide goal to reduce mortality and morbidity,
 monitor progress, and recommend course corrections to attain the identified goal, and make inroads,
 and progress with constituents and communities. Ensure that the Council body is representative of
 informal and formal leaders, including community representatives, congregations (faith-based),
 corporate, and civic sectors.
- 2. Provide opportunities to create employment pathways for residents and, in particular, training as health workers, doulas, and entry-level positions that establish a career ladder and professional progression in the field. Such pathways can begin to root economic security and productivity in underserved and under-resourced communities and provide yet another impetus for community engagement. Community colleges with state and federal funds, and national or local philanthropic support could be starting points for such a program.
- 3. Establish required training for all medical service providers and support future planning and cocreation of a vision that integrates a power-sharing model with the communities served. This should include management, entry-level, and support channels with learning opportunities (formal

and informal training, in-class, and community communication systems). This training will clarify the social, economic, and cultural framework of the communities served and act as a bridge to adopting culturally respectful skills when approaching or interacting with patients, families, and communities of color in general.

4. Consider a statewide "Youth Corps" pilot to train and employ youth and young adults to become community health workers and neighborhood health ambassadors. This could also incentivize health career paths, and could be augmented through support for studies at a community college, public college, or university (e.g., Atlantic Cape Community College, Camden County College, Mercer County Community College, Montclair State University, Rutgers University, College of New Jersey, and others).

Addendum

A Possible Scenario: Everyone Has Something Offer: The Assets-Based Community Development Model (ABCD)

Co-Creating Structural Change

- Cultivate and engage audiences (e.g., mothers and women of color, residents).
 - Determine leadership development strategies
 - Ask!



- 2. Identify Community Assets (human, physical, informal, social, etc.)
 - What are our community's strengths and successes?
 - How do we use these assets to address the challenges we face?
 - What can I share at the table? (e.g., my lived experience, expertise, resources, leadership, networks, etc.)
- 3. Bring together to work together through dialogue and identification of shared aspirations
 - Informal (small groups, at community sites, hosted by a local leader who has crosscommunity/cross-sector respect and trust)
 - O What is our shared history?
 - o Identify possibilities and "demystify" existing power structures.
- 4. Identify community assets (human, financial, social, political, leadership, etc.)
 - What is present in the community that can help resolve the issue?
 - What is present that can lead to the solution(s)?
 - What can we add (e.g., representation, community, lived experience, expertise) that will enhance how we create results?

- 5. Find common ground and link community assets to co-create solutions
 - What to give up/ what to keep/ what to share to advance maternal and infant health?
- 6. Determine who does what by when: How is communal leadership expressed?
 - What will we do in 30 days? Where will our work be in 60 days? What will change in 6 months?
 - What are the guardrails we put in place so that community-driven is the core value?
 - How will we assess our progress? (short and long-term)
 - O What are the accountability processes to the community?
 - Do all stakeholders concur?
 - How evaluation will occur (including course corrections, appreciative inquiry for continuous learning, etc.)
- 7. Honor and Respect Ownership: How does the community retain control and power in the process?
 - How do we celebrate our accomplishments and milestones?

Achieving Racial Equity in Maternal and Infant Health through Community Engagement: A How to Guide

Overview

"Every mother deserves the opportunity for a healthy birth experience and a healthy child.

Skin color should not impact the quality of care received or chances of surviving childbirth,

nor should it determine whether children live to see their first birthday."

- First Lady Tammy Murphy -

New Jersey (9/24/2019)

All too often, the residents and families of under-resourced and underserved communities face daily struggles for their survival. Divestment and abandonment by the public and private sectors have produced lower quality schools for children, substandard housing, scarce jobs—all of which lead to income inequality and troubling disparities in mental, emotional, and physical health. These economic, social, and political conditions create dangerous conditions for poor and low-income families and compromise future generations' healthy development.

"Why can't the state make this a win-win situation and promote services in a more consolidated manner?"

When considering approaches to these challenges, there is only one place to start—with the profound resilience within these communities. After generations of perseverance against poverty, structural racism, and continuous microaggressions, informal and formal networks have woven a strong social fabric. Examples of these assets include parents and neighbors who patrol school routes to ensure the safety of children; elderly residents gardening or collectively planting vegetable gardens; or residents cleaning empty lots strewn with debris and garbage. As expressions of agency by residents to engage in creating safe and inviting communities, these are examples of community engagement.

Community engagement can occur at a macro or micro level. From significant institutions to grassroots organizations to informal leaders, community engagement takes on shapes and forms designed to increase the voice and participation of community members, and allied stakeholders in the self-determination of their communities. The Centers for Disease Control defines it as:

"The process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people."

Nurturing community engagement and people-focused participation requires an unyielding commitment to build broader and more inclusive circles of relationships across communities and multiple sectors. This process allows for shared aspirations to surface and to explore solutions that promote the common good.

But community engagement is only the first step. Galvanizing residents to demonstrate personal agency requires support, time, focus, and patience in helping build knowledge and leadership skills. Subsequent steps for long-term impact and evidence-based results require a commitment to power-building and power-sharing.

Power-building and power-sharing require a paradigm shift in New Jersey's health and wellness mental models. This shift in thinking and policies, programs and practices, must be rooted in the creation of relationships and trust-building across multiple stakeholders and sectors, as well as investment in financial and non-financial investments; informal and formal links and relationships; cross-sector collaboration; training and skills development; and the willingness to amplify the voice and space of families and communities impacted by the loss of mothers or infants.

Several themes of common concerns surfaced during meetings with New Jersey mothers (primarily women of color), institutional leaders, and service providers. Their observations provided a context for the interaction among patients, hospitals, and medical staff, and the patterns of treatment and behaviors experienced by women of color preparing to deliver a baby. Inconsistencies in the quality of care provided, lack of respect, demeaning interactions and microaggressions, poor professional treatment, and the shortage of resources (including language interpretation services for non-English speakers), were consistent themes throughout these meetings.

Yet, it is those most affected who must be at the table when public officials and political leaders decide how to address their concerns. The process of engaging community members, families, mothers, and women of color in particular, in the co-creation of solutions, can begin with guiding questions that emphasize shared aspirations and common ground. These could include: Why should this be of concern to all of us? How do behavior patterns, biased practices, and internalized and overtly racist policies diminish the quality of life

"One significant need is to address the perceptions health care providers have about pregnant women of color. There should be required training for all health care providers. Could this be a metric of care?"

Agency Director

of women and infants? (particularly in their pre-, during, and post-pregnancy treatment and care?) What do we change? How will we change, and what is our guiding North Star?

The Current Community Engagement Landscape: Actors and Opportunities

Community Coalitions and Networks

Visualizing linked aspirations and goals can connect the desires and needs of residents, to the solutions that emerge and are presented to impacted communities by medical health providers.

There are several efforts undertaken by organizations, networks, and service providers to tackle New Jersey's maternal and infant health dilemmas. Key players include:

- <u>Maternal and Child Health Consortia</u>, which are comprised of perinatal providers, hospitals, and nonprofits.
- Partnership for Maternal and Child Health of Northern New Jersey includes birthing centers, hospitals, and medical centers.
- <u>Central Jersey Family Health Consortium</u> focuses on working with women and newborns.
- Southern New Jersey Perinatal Cooperative has a menu of resources, programs, and an advocacy plan in support of a "regionalized standard of care."
- <u>Planned Parenthood of Southern New Jersey's Thrive Coalition</u> draws together health advocates and providers working on women's health and reproductive rights.

As well, there are emerging, and established organizations focused on the health and wellness of women, children, and families. Situated "in the community" these include:

- Camden Coalition of Healthcare Providers
- Children's Futures (Trenton)
- Children's Home Society (Trenton)
- Healthy Women, Healthy Families (Atlantic City)
- Melinated Moms (Linden)

These resources and services encourage individual, family, and community engagement in the quality of life and health improvement efforts. Moreover, "community-conscious" and community-based approaches include an array of resources such as counseling and wraparound services, health fairs, public advocacy, community education, parenting classes, medical care, and other activities designed to address the health of mothers and infants, and the agency of families.

New Jersey-based civic and nonprofit groups, including academic institutions, the NAACP, the Association of Black Women Physicians of New Jersey, the New Jersey Coalition Against Sexual Assault, the African American Chamber of Commerce of New Jersey, 100 Black Men of New Jersey, Latino Action Network, and the Latin American Legal Defense and Education Fund, and others, can be active partners in carrying forward a plan to address maternal and infant health disparities.

Faith-Based Presence and Voice

The faith-based community is another sector of importance and relevance in addressing the state's maternal and infant health care crisis. Churches and congregations, and their ministries (e.g., shelters, food pantries, health, family and spiritual counseling, job assistance, legal assistance, and more) can be pivotal partners in reaching out to community members and in targeting outreach to teenagers, adults, and women of color in general.

Faith-based institutions play a significant role in the Black and Latinx communities. They are centers of spiritual support and anchors in communities of color. They serve as places of refuge and solace in times

"Birth does not happen without the community."

Montclair State University Faculty Member

March 2020

of trouble (e.g., slavery, ongoing periods of heightened racism, civil unrest, deportation, separation of families, nativism, and xenophobia) in the US. The unique relationships between a congregation and its pastor or minister can help promote equity in maternal and infant health and care. The "power of the pulpit" can educate, create awareness, and shift mindsets. It can also challenge institutional racism and health disparities that impact women of color before, during, and after their pregnancies, and the subsequent care of their newborn child. There are already several efforts by faith-based bodies to address work in poor communities, address anti-racism, and bring together diverse faith communities in the Garden State. These include:

- Faith in New Jersey,-based in Camden, is a multi-faith and multi-racial network with a social and economic justice plan and is an affiliate of the Faith in Action Network. http://faithinnewjersey.org/
- The Episcopal Diocese of New Jersey's Anti-Racism Ministry provides anti-racism training. https://dioceseofnj.org/antiracism/
- The New Jersey Synod of the Evangelical Lutheran Church of America provides anti-racism training and consultations. https://www.njsynod.org/anti-racism.
- Fellowship of Churches of Atlantic City and Vicinity is an ecumenical organization with more than 50 years of collaborative efforts and over 11,000 members.
 - https://www.facebook.com/FellowshipofChurchesofAtlanticCityandVicinity/?pageid=2030963277228147&ftentidentifier=2487033231621147&padding=0
- Trenton Ecumenical Area Ministry (TEAM) is a broad-based Christian effort that has served as New Jersey's ecumenical voice for the poor since 1941.

Other nonprofit groups, such as Planned Parenthood of Southern New Jersey, have formed an interfaith council. Lastly, and just as critical, is New Jersey Department of Health's support for the Camden Coalition of Healthcare Providers and its Faith in Prevention Initiative. This partnership engages churches and mosques in promoting healthy lifestyles. Given the nine faith-based organizations that comprise this initiative, this is a promising vehicle for addressing maternal and infant health disparities and amplifying religious action to address the current crisis.

Philanthropy

Two other sectors are vital to changing New Jersey's mindset on maternal and infant health. First, the state's philanthropic sector can partner to support community members in acquiring the training and skill-building to enable them to be fully engaged in a more comprehensive and transparent health delivery system.

Secondly, foundations can support grassroots and community-based organizations, hospitals, and clinics in efforts to create a racial equity framework and to advance relationship-building among these distinct

groups. These sectors have the reach and resources to support new approaches to eliminating pervasive health disparities.



As an example, the Council of New Jersey Grantmakers can become an essential ally to help prioritize and promote community-building and power-sharing with the state's public health ecosystem. The Robert Wood Johnson Foundation, New Jersey Health Initiatives, the Burke Foundation, the Atlantic Community Fund, and others (particularly those supporting communities impacted by maternal and infant mortality and morbidity), are a few of the state-based philanthropic bodies that could partner to improve maternal and

infant health in New Jersey.

New Jersey is also geographically positioned to cast a broader net in support of maternal and infant health. For example, New Jersey's proximity to New York-affords consideration of a regional link to engage New York's robust philanthropic community. Partners could include Philanthropy New York and Candid (formerly the Foundation Center).

Tapping the Council's extensive membership base can augment support from family, corporate, and private foundations. Engaging this sector is strategically essential, and will help move resources (financial and otherwise) to seed community engagement, training, and evidence-based solutions that will ensure sustainable change in the public health system.

Corporate and Business Sector

Another potential partner is the state's vibrant corporate and business sector. New Jersey is home to several of the world's leading pharmaceuticals. These include Novartis, Bristol-Myers Squibb, Merck & Company, Bayer Healthcare, Johnson & Johnson and others.

This rich panorama affords the state's executive leadership the opportunity to invite and engage this sector in support of the First Lady's Nurture NJ effort. Some work is already taking place; for example, Merck for Mothers works to "...[C]reate a

Pro-Baby, Pro-Mom

"We can make New Jersey a pro-baby, pro-mom state. The culture needs to change, but this is doable.

Maternal child health has to include an education component, a support network, and a continuum of support services that draws in and engages to-be-mothers, partners, spouses, significant others, and families."

Trenton Service Provider
March 2020

world where no woman has to die giving life," and Merck's Safer Childbirth Cities Initiative promotes local solutions in urban centers with problematic maternal mortality and morbidity rates.

Merck's ten cities include health coalitions in Camden (Camden Coalition of Healthcare Providers) and Newark (Greater Newark Healthcare Coalition).

More recent civil unrest and public outcry have driven home the need for all sectors to address structural racism and social disparities. Johnson & Johnson Family of Companies' CEO recently sent a

letter to all its employees. In part, it read, "As the CEO of the world's largest healthcare company, I must state unequivocally that racism in any form is unacceptable, and that Black lives matter. Our company is committing \$10 million to fighting racism and injustice in America – a pledge that will span the next three years."

Thus, this is an opportune time—also known as a Kairos moment—for New Jersey. Communities and residents historically marginalized from decision-making processes can become central voices and players in helping dismantle inherent and systemic disparities, that endanger and disrupt their quality of life, health, and wellness.

Building Muscle for Community Capacity, Scaffolding Leadership, and Power-Sharing: The Assets-Based Community Development Approach

A commitment to community engagement, power-building, and power-sharing is a potent pathway for altering this public health landscape. It is a beginning for advancing new practices and interventions that mitigate the suffering and trauma of communities of color, and specifically of women of color before, during, or after their pregnancy.

New Jersey is a leader and can join other states (e.g., California, Massachusetts, Nevada) that have attained evidence-based outcomes and successfully engaged residents, communities, and the health care sector. Starting this journey requires openness, creativity, and transparency. It also requires the willingness to consider traditional ways of community participation (media, public hearings, dialogues, local events) and emerging models of involvement by community residents and local organizations linked to mothers and families, and others such as online virtual organizing, and social media

ABCD Defined

ABCD is a methodology that considers local assets as the primary building blocks of sustainable community development; ABCD draws upon existing community strengths to build stronger, more sustainable communities



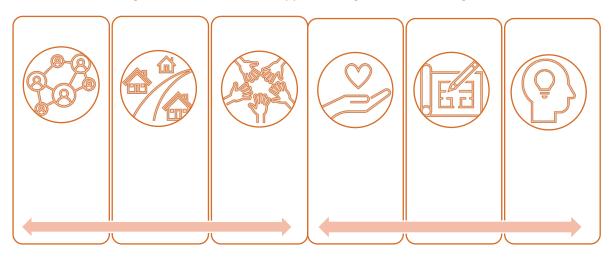
platforms to ensure a multi-racial, multi-ethnic and multi-generational approach.

The Assets-Based Community Development Approach (ABCD)

Nurture NJ's community engagement and power-building thrust can be grounded in an asset-based community development approach (ABCD). The ABCD approach is useful for bringing forth assets (known and unknown), and strengths such as neighborhood or community ecosystems, and informal and formal structures (e.g., leaders, groups, and individuals). This approach could then build on existing resources and be an opportunity for engaging various audiences and sectors that have participated in collaborative planning, decision-making, or community-grounded leadership. (See Addendum for additional information.)

Moreover, this approach requires a process for voluntary participation, transparency, and a pledge to empower participants—regardless of their educational attainment, social standing, or economic class. Fundamental to this process is a mindset that all participants can contribute and that the process will

nurture relationship-building and trust-building. At its core, an ABCD approach to community engagement and power building acknowledges that every community resident has something to offer and to contribute. A high-level view of such an approach might look something like this:



Foundational Components of a Maternal and Infant Health Community Engagement, Power Building, and Power Sharing Approach

To turn the tide on maternal and infant health, particularly in communities of color, public officials and political leaders must be at the forefront of the effort and stimulate a new mindset and new public health principles. For example, they must support the leadership and self-sufficiency of communities of color. Secondly, they must promote health equity. Lastly, they must help alter the existing power dynamics and structures (e.g., women of color are equal decision-makers in all pre-, during, and after-pregnancy decisions). This new paradigm places equal value and respect on the lived experiences of residents, women of color, and affected communities. Existing power dynamics and medical and health structures can change to power-sharing through community building, leadership, and racial and public health equity. This critical pivot alters established norms of exclusivity within the existing decision-making power structures and leadership processes. This shifts the public health system to one of voluntary participation, nurtured leadership, and ownership by under-resourced and underserved residents and their communities. In summary, residents, and communities most affected and impacted by maternal and infant mortality or morbidity co-create and "own" the solutions and practices that could ultimately, eradicate New Jersey's maternal and infant health care crisis.

Section II.6 Facilitating Cross-Sector Collaboration in Ensuring Healthy Mothers and Infants for Nurture NJ

Shanta Whitaker & Elizabeth S. Lee

Through the strategic planning process, nine sectors, or stakeholder groupings, were identified as the most important actors in Plan implementation. Each sector holds power and influence to ensure that maternal mortality is reduced by 50 percent over five years, and that disparities in birth outcomes are eliminated by race and ethnicity. The health care sector and state leaders must be at the forefront of every sector's plans to ensure that New Jersey becomes a safer place for birth; these actors undoubtedly take a leadership role. This section seeks to delve into sectors not commonly seen as having a role in maternal and infant health. All sectors have a role in making New Jersey the safest place to give birth. Health entities and state/local government have a role in catalyzing and enhancing multisectoral collaboration.

Academia

Academia has an important role to play in reducing maternal and infant mortality in New Jersey in various ways through research, thought leadership, data analysis, and innovation. In addition, schools and universities serve as the training ground for maternal and child health public health experts, clinicians, and other professionals necessary to ensure that New Jersey will become and remain the safest place in the US to give birth. Currently, there is a dearth of Maternal and Child Health (MCH) research on New Jersey available to the public, as evidenced by few R01 grants and publications specific to the state. However, there is still great work being conducted at some of the top academic centers within New Jersey's university/college system.

Many professors at schools across the state of New Jersey are working to help their communities, some of which are more severely impacted by maternal and infant mortality and morbidity:

- Rutgers University has a New Jersey Department of Health-funded Integrated Population Health
 Data Project (iPHD) which resides in the Center for State Health Policy. iPHD supports population
 health research to improve the health and well-being of New Jersey residents, which could easily be
 expanded to include research that focuses on improving health outcomes for moms and their babies
- The College of New Jersey (TCNJ) the Center for Integrative Wellness has a partnership with a school in Trenton that allows them to help families with infant stress management and provide mental health services. Several TCNJ faculty members and students also work with Project TEACH in Trenton. The Project TEACH program is a comprehensive program geared towards pregnant or teen parents who are at risk of not finishing secondary school. TCNJ personnel teach these young people how to care for their infants, proper nutrition, and general care
- John S. Watson Institute for Public Policy at TCNJ has spearheaded initiatives that focus on or relate to maternal and infant health ranging from policy development to serving as an incubator for nonprofit development. Some notable work has been done in the city of Trenton to create access to

- fresh produce and nutrition education classes for residents. In addition, the Institute was the birthplace of Children's Futures, a Trenton-based nonprofit with a mission to improve the health and welfare of mothers and infants that provides Health Start programs.
- Stockton University professors Drs. Betsey Erbaugh, Christina Jackson, and Sreelekha Prakash teach about the impact of redlining on Atlantic City communities. Redlining, combined with denial of various services by federal government agencies and local governments as well as the private sector, has had a downstream trickle effect on health outcomes within Atlantic city as well as other communities within New Jersey. Students are studying the sociological perspective on societies and implications for people facing food deserts, loss of jobs from the casino, etc., which all play a role in health outcomes.

Top Collaborator Candidates: Private funders, community, and grassroots organizations

New Jersey colleges and universities are fertile grounds for collaboration and spearheading grassroots movements around improving maternal health in the communities in which they reside. For example, students taking urban sociology courses at Stockton learning about the impact of redlining on Atlantic City communities conduct townhalls and other community listening tours/interviews to gain the perspective of the communities on issues such as food deserts, loss of jobs from the casino, and how they are affecting health. Stockton could harness the impact of their work by partnering with local and state-level community and grassroots organizations to use community recommendations to develop policy/interventions to alleviate what is hurting the community. This, combined with private funding to supplement, would help pregnant women, mothers, and their babies to live in contexts that are supportive of and improve their health outcomes. Opportunities abound to partner across academia and with all the other sectors, especially state and local government agencies to form an academic center of excellence focused on the development of innovative plans to address maternal and infant health disparities.

PROPOSED AREAS OF COLLABORATION:

PROJECT	Academic Leaders	Private Funders	Business Leaders	Community / Grassroots Organizations	State agencies
Analyze access to and utilization of social services and maternal/infant health outcomes in partnership with community and grassroots organizations	Lead			Partner	
Evaluate the effectiveness of ongoing state- level programs for moms and babies in partnership with community and grassroots organizations.	Partner			Partner	Lead

PROJECT	Academic Leaders	Private Funders	Business Leaders	Community / Grassroots Organizations	State agencies
Conduct an economic burden study of maternal/infant mortality tied to/incorporate future projections of the NJ New Jersey workforce	Lead		Partner		
Conduct a larger scale mapping of "maternal hot spots" mapping social services, food access, and maternal/infant morbidity/mortality rates	Lead	Partner		Partner	
Develop metrics to assess the success of maternal and infant mortality and morbidity interventions	Lead			Partner	Partner
Develop racial equity in maternal/infant mortality business cases in partnership with businesses and community-based organizations	Lead		Partner		
Develop special employment pathway programs specific to under-resourced pregnant women and moms to gain professional training and soft skills to succeed on the job market	Partner		Lead		

Business/Employers

Overview

Businesses play a big role in community development; they provide jobs, and downstream benefits for healthcare, food, and having other social needs met. Often, companies want to give back to their communities and support positive social change. The private sector has always played a critical role in women's reproductive and maternal health, from developing drugs and innovative technologies to running private clinics. Because some businesses may be reticent to come to the table, a business case must be presented to incentivize companies in participating. To engage companies interested in such activities, Nurture NJ leaders should identify key corporate players and bring them to the proverbial table. Getting business buy-in could be accomplished by presenting the business case of addressing maternal and infant mortality and morbidity and of racial equity to them. The business case would need to highlight the downstream effects of reducing disparities and maternal/infant mortality, such as an increased future workforce and retention of the workforce due to the mother's improved health.

Furthermore, New Jersey has a concentration of pharma companies, including Johnson & Johnson and Merck, and large companies, such as Gerber Baby Food and Campbell Soup, that are poised to help execute programs or initiatives to decrease maternal and infant mortality and morbidity in New Jersey. One way that businesses could leverage their power to improve maternal and infant care is by pressuring insurers to bundle care in an effort to prevent unnecessary cesarean sections. ¹³ However, businesses do not have to be large to have an impact; small business owners can be incentivized to provide support to WIC and SNAP families. Small stores, bodegas and colmados could receive financial incentives to advertise in multiple languages, and have attractive displays so that the use of WIC becomes normalized rather than stigmatized.

Top Collaborator Candidates: academia, housing, community and grassroots organizations, and food/nutrition

Collaboration is already underway in New Jersey—Campbell Soup has a foundation that helps to provide education around nutrition and increase access to healthy foods in food deserts within Camden. They achieve this by partnership with local businesses, and community service/grassroots organizations. Johnson & Johnson is currently spearheading a Quickfire Challenge, in collaboration with the Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN) to improve maternal and infant health. ¹⁴ Business owners, academia, and state/local government should be drawn into this work as well.

PROPOSED AREAS OF COLLABORATION:

PROJECT	Academic Leaders	Private Funders	Business Leaders	Community / Grassroots Organizations	State agencies
Invest in community organizations that promote/provide wrap-around services for pregnant moms and babies			Lead	Partner	
Drive innovation in maternal and infant health by sponsoring challenges like the one Johnson & Johnson is currently undertaking	Partner		Lead	Partner	
Partner with academia and community service/grassroots organizations to conduct research around workforce readiness and supporting moms and pregnant women in the workforce	Partner		Lead	Partner	

PROJECT	Academic Leaders	Private Funders	Business Leaders	Community / Grassroots Organizations	State agencies
Work with state government and community and grassroots organizations to improve personal economy, by focusing on women's education and employment. To get buy-in, present the business case for investment in mothers, families, and babies		-	Lead	Partner	Partner
Contribute to the development of equity training infrastructure for state/local government		Partner	Lead	Partner	Partner
Support place-based models		Partner	Lead		
Expand programs such as Internet Essentials, where businesses such as Comcast are providing low-cost computers and internet access to low-income families	Partner		Lead		

Funders

Overview

Private funders are more likely to focus on emerging issues, allow an applicant to pool resources with other funders, and be more flexible in providing funding for unique needs and circumstances. Compared to public funding, an applicant would avoid the bureaucratic requirements for administering grants. In addition, full length, complex proposals are not always necessary. Another benefit of private funding is that, in instances where funders cannot provide financial support, they can often provide alternative forms of assistance, i.e., software/hardware donations, materials, expertise, etc.

New Jersey provides a home for some of the largest private foundations as well as businesses (as described in the business sector section) such as Merck for Mothers and the Robert Wood Johnson foundation (RWJF), which are doing innovative work within New Jersey to address maternal and infant morbidity and mortality. Merck for Mothers recently released a report detailing funding that it provided to 12 states to review their maternal mortality review data to understand some of the key underlying factors resulting in maternal mortality and then develop innovative ways to address them. ¹⁵ North Carolina, one of the funded states, discovered that cardiovascular disease was a big contributor to maternal death after reviewing their maternal mortality review board data. With this knowledge, they

partnered with state and community organizations to prevent chronic disease and improve preconception health as well as launched a pilot project to address the health needs of women with severe cardiovascular risk factors that were also of a reproductive age and at risk for maternal morbidity and mortality.¹⁶

RWJF collaborates with organizations within New Jersey as well as across the country to promote healthy communities. One way that RWJF is tackling maternal mortality and morbidity is by funding community organizations that have a pulse on needy communities. For example, they funded the Louisiana-based National Birth Equity Collaborative (NBEC) to develop a "metric for patient-reported experiences related to respectful care and trust in childbirth and pregnancy." ¹⁷ This was mutually beneficial: RWJF was able to-obtain-insight and entry into communities where NBEC had established relationships with community members, which allowed them to capture patient experiences in a way that RWJF would not be able to.

Top Collaborator Candidates: Academia, housing, community and grassroots organizations, and food/nutrition

The ground is fertile for private funders to collaborate with key stakeholders in academia, housing, community and grassroots, and food/nutrition. For example, RWFJ has several funding mechanisms ranging from research on housing policies which promote equity to a Culture of Health Leaders program that combines leaders from all sectors to build healthier communities. These existing programs could be approached from a maternal and infant health perspective to improve birth equity. Other private funders could create a call to action for proposals/fellowships around maternal and infant health research and innovation, and for-programs/projects that could address housing and other social service needs. All collaborations and funding mechanisms can be funneled through the Nurture NJ Ecosystem model to determine areas of priority for improving maternal and infant health.

Proposed Areas of Collaboration

PROJECT	Academic Leaders	Private Funders	Business Leaders	Community Grassroots Organiz-ations	State agencies
Provide flexible funding for academia and community and grassroots organizations that which have long-standing connections with communities impacted by maternal and infant mortality/morbidity	Partner	Lead		Partner	
Create funding mechanisms for "maternal and infant health disparities clinical/public health fellows" who will work in communities with high rates of maternal and infant mortality/morbidity and serve either at the patient or population-level	Partner	Lead		Partner	Partner
Develop program for housing and academia focused organizations to research and understand gaps in social services and housing needs.	Partner	Lead		Partner	Partner
Create funding mechanisms to engage in community-participatory research to understand the best ways to eradicate food deserts within communities with high maternal and infant mortality and morbidity	Partner	Lead		Partner	Partner
Support place-based models	Partner	Co-Lead	Partner	Partner	Co-lead
Fund development of equity training infrastructure for state/local government	Partner	Co-Lead			Co-lead

Service Providers // Housing

Overview

Today New Jersey remains one of the most segregated states in terms of housing because of historical zoning, and redlining practices.¹⁹ The housing inventory is lacking. There are blighted neighborhoods with empty buildings or poor housing with no access to functional appliances, lacking open space and greenery for children. Many families are intergenerationally packed together, living-under one roof. Further, Black Americans are more likely to either live in low- quality housing or be housing insecure, which is defined by having housing costs that hinder a person's ability to take care of other necessities such as food, transportation and internet access. Housing insecurity means people live in crowded or low-quality housing, unsafe housing, and unsafe sleeping arrangements, with frequent moving, or living with family and friends, or in some cases, homelessness.²⁰

Housing insecurity can cause toxic stress which can impact both mother and child. It is linked to preterm birth, lifetime health outcomes for the child, and can contribute to infant mortality. Extreme housing insecurity or homelessness can have an even greater impact on pregnancy. Women experiencing homelessness were more than twice as likely to experience a complication that affected their health during birth and almost twice as likely to have an early or threatened labor or a hemorrhage during pregnancy than the comparison group. Participants in the Nurture NJ community dialogues raised issues about the difficulty pregnant women and/or moms can face when trying to access safe housing. One woman described how individuals need a referral to receive shelter, but no direction is provided on how to obtain a referral. This ambiguity adds unnecessary stress to mothers trying to provide a home for their children. Having housing stability allows mothers and pregnant women the ability to focus on their health and the well-being of their children. Permanent housing helps women to get back on their feet.

Top Collaborator Candidates: Academia, business, private funders, and community and grassroots organizations.

Key stakeholders pointed out existing multisectoral partnerships that are helping to increase access to safe and affordable housing for low-income individuals. These partnerships could easily be expanded to consider the unique needs of pregnant women, moms, and their families:

- Housing Community Development Network of New Jersey (HCDNNJ) is working to bring housing and other social services organizations together by using a community health needs assessment to support the communities they serve.
- Catholic Charities focuses on housing, homelessness, and prevention within various New Jersey communities such as Burlington, Mercer, Ocean, and Monmouth Counties. One of their key programs, "Keeping Families Together", is a program to keep mothers and children together by providing housing vouchers.

- St. Joseph's Medical Center has been focused on building supportive housing. There are good national models of multisectoral collaborations; Catholic Charities works with St. Joseph's to provide the wrap around services, while the hospital built the housing.
- Camden Coalition uses the Housing First model to address housing insecurity among their high risk, chronic disease patients.

PROJECT	Academic Leaders	Private Funders	State Agencies	Community / Grassroots Organizations	Service Providers – Housing
Work with community and grassroots organizations to glean best practices from other housing programs across the country which also support growing families.				Partner	Lead
Collaborate with private funders, state/local health departments, and business to develop/utilize evidence-based models to create safe homes for pregnant individuals, parents, and their babies.	Partner			Partner	Lead
Work with state/local government and community service/grassroots organizations to establish transparent tracking and accountability for affordable housing to ensure that units are developed and equitably allocated to pregnant women and families with young children.	Partner		Partner	Partner	Lead
Work with state/local government and private funders to establish a centralized mechanism for quantifying and describing the housing insecurity status of pregnant women and families with young children.			Lead	Partner	Co-lead
Collaborate with private funders, academia, and state/local government to conduct heat mapping analysis of affordable housing availability in cities/townships most impacted by maternal and infant mortality; assess need of mothers that reside in these areas	Co-lead	Partner		Partner	Lead

Service Providers // Food and Nutrition

Overview

Food insecurity is defined as a lack of consistent access to enough food for an active, healthy life and is tied to a dearth of available financial resources for food at the household level.²⁵ Food insecurity during pregnancy is associated with stress, disordered eating, and greater postpartum weight among women who are already overweight.²⁶ Food insecurity is a complex problem and does not exist in isolation for low-income families. Many of the same families also struggle with issues such as affordable housing, medical costs and low wages.²⁷ Black Americans and Hispanics, low-income families, and households headed by a single parent are more likely to have a higher prevalence of food insecurity.²⁸

Food and Nutrition's Primary Role: Develop an equitable food system that optimizes the health of pregnant women, mothers, and newborns:

To create an environment where mothers can have safer births, it will be important to address inequities in the production, distribution, and pricing of food. For example, the use of locally grown foods, selling locally, farm to school and farm to business, would help to provide jobs and keep money within the local economy. Within New Jersey, there are federal programs which are administered at the state and local level, such as the Supplemental Nutrition Assistance Program (SNAP), the Special Supplemental Nutrition Program for Women, Infants and Children (WIC), and the National School Lunch Program (NSLP). In 2017, SNAP lifted 3.4 million people out of poverty.²⁹ Despite this success, it is estimated that 29 percent of food-insecure individuals live in a household that does not qualify for assistance.³⁰ In the case of WIC, there is plentiful assistance available, yet many potential beneficiaries fail to take advantage of it. Nationally, of the 13.9 million individuals eligible for WIC only 7.6 million participated in the program in 2016, representing only 55 percent utilization.³¹ A similar trend was seen in New Jersey, with 285,000 eligible for WIC and only 153,000 participating (54 percent utilization).³² This is where multi-sectoral collaboration can help fill the gaps and increase awareness of available and supportive state-level programs.

Top Collaborator Candidates: Academia, business, private funders, and community and grassroots organizations.

New Jersey stakeholders also shared the innovative ways that the food and nutrition sector is collaborating with business, private funders, and community and grassroots organizations to increase access to nutrient-dense food in food deserts. For example, Atlantic City legislators are working to get a grocery store through a ShopRite partnership. They are partnering with the Casino Reinvestment Development Authority and the non-profit Uplift Solutions, to build a grocery store that will cater to the needs of the Atlantic City community. They are also collaborating with community service organizations to hold townhalls and focus groups to understand what Atlantic City residents need. This example could be replicated in other areas of New Jersey to ensure that pregnant women, moms, and their babies have access to the food that is necessary to thrive and be healthy.

Service Providers//Environmental Groups

Overview

The environment can have negative impacts on maternal and infant health.³⁴ Across the state, there are pregnant women/moms/children and families that live in areas disproportionately burdened by environmental hazards, unhealthy land uses, psychosocial stressors, and historical traumas, all of which drive environmental health disparities. Concentrated poverty increases exposure to environmental toxins and, unfortunately, residents of low income neighborhoods and communities tend to have access to fewer and lower quality resources that support child development, such as safe and affordable food, parks and recreational facilities, schools and child care facilities.^{35,36} Black Americans, Hispanics, and other under-resourced communities tend to live in these hazardous environments; maternal and infant mortality and morbidity are exacerbated in these areas. Unfortunately, these communities tend to be underserved by public and private entities that create and enforce environmental hazards and are underrepresented in decision-making processes.

Historically, redlining, and other discriminatory housing practices placed communities of color in neighborhoods with higher levels of contamination and other environmental hazards such as lead, and poor air quality caused by pollution. Studies have shown that a disproportionate number of New Jersey residents reside close to an environmental hazard and are more likely to feel the effects downstream through higher rates of asthma and environmentally-driven low infant birth weight. To address these issues, both state and local governments are working together to conduct testing and do remediation of hazards in housing and in the community. However, there is ample space for multisector collaboration to amplify and expand existing efforts.

In addition, community-led environmental groups must consider how best to incorporate more greenspaces in urban environments. Greenspaces have been shown to promote mental health, boost the immune system and improve pregnancy and morbidity outcomes. ^{40,41} Greenspace would help promote a nurturing environment for moms and their babies and aid in improving health outcomes.

Top Collaborator Candidates: Academia, business, private funders, and community and grassroots organizations

Within New Jersey, academia, business, private funders, and community and grassroots organizations could pool their resources together to address environmental hazards. They could rally around existing efforts to reduce exposure to hazards as the New Jersey Department of Health is doing around lead abatement.

PROJECT	Businesses	Private Funders	State Agencies	Community / Grassroots Organizations	Service Providers – Environmenta I Groups
Collaborate with community and grassroots organizations to organize community/neighborhood cleanups	Partner			Partner	Lead
Work with academia, private funders, and state/local government to continuously improve the Healthy Community Reports produced by the Department of Environmental Protection, and utilize these Reports to design strategies to reduce the impact of hazards	Partner	Partner	Partner	Partner	Lead
Partner with private funders to offer grants for innovation around reducing exposure to environmental hazards for pregnant women, moms, and infants.		Partner	Partner	Partner	Lead
Work with business to provide incentives around creating a green footprint and reducing toxic output from facilities.	Partner		Lead	Partner	Co-lead
Continue to build and expand the Community Collaboratives, partnering with public sector, private funders, and community/grassroots organizations to develop greenspaces in urban centers and in areas of New Jersey with higher than average maternal and infant morbidities and mortalities.	Partner	Partner	Co-lead	Partner	Lead

Service Providers//Transportation

Overview

Transportation can serve as a huge barrier to healthy outcomes. New Jersey has a weak transportation infrastructure, which can make it hard for pregnant women and moms to get to necessary pre- and postnatal appointments or be able to access other social services or food. There are communities where a bus or train is not within a one-mile radius from an individual's home. Cities like Trenton are devoid of effective means of transportation for residents. Further, in the more under resourced areas across the state, cars are a necessity; yet the costs associated with insuring a vehicle in New Jersey are exorbitant and out of range for New Jersey residents who are already hard-pressed to meet their basic needs. In

addition, there are few transportation sources that exist for Spanish-speaking residents and residents who speak primarily a language other than English to get translation services, due to a lack of staff.

Transportation's Primary Role: Carry mothers and infants to healthcare, employment, social services and food and nutrition

Women who participated in Nurture NJ community dialogues shared that they wait for several hours to take public transportation or must rely on a friend or family member who is available; then they arrive at their medical appointment to wait for hours to be seen. ⁴² This is not unique to the women in these dialogues: studies highlight the role of transportation in regular, consistent access to healthcare. ⁴³ Furthermore, a poor transportation system greatly hinders access to nutritious food, which is important to the health of both mother and child.

Top Collaborator Candidates: Business, private funders, and community and grassroots organizations

Within New Jersey, accessible transportation is a glaring need for pregnant women, moms and infants. Within the past few years, the state government-run program Access Link has expanded services for pregnant moms to get them to medical and other social services appointments. However, the trip must be pre-booked and fall within Access Link's designated transportation zone. Business, private funders, and community and grassroots organizations can help to bridge the gaps by providing additional funding and support for this program as well as implement new and innovative programs.

Areas for Transportation to Innovate and Collaborate

PROJECT	Businesses	Private Funders	State Agencies	Community / Grassroots Organizations	Service Providers – Transportatio n
Multisectoral pooling of financial resources to provide funding for transportation; work with local government to improve infrastructure in transportation poor townships and cities	Partner		Co-lead	Partner	Lead
Increased partnership with businesses and private funders to build upon established Lyft and Uber initiatives to provide transportation to doctors' appointments, grocery shopping and other services for pregnant women, moms and their infants	Partner	Partner	Partner	Partner	Lead

PROJECT	Businesses	Private Funders	State Agencies	Community / Grassroots Organizations	Service Providers – Transportatio n
Work together with state/local government to secure federal funding to increase transportation efforts (buses, bike shares, etc.) and improved infrastructure in poorer towns		Partner	Partner	Partner	Lead

State Agencies//Criminal Justice

Overview

The US' incarceration system doesn't adequately care for pregnant women, before, during, and after childbirth.⁴⁴ Women in prison who arrive pregnant are considered high risk, which is often exacerbated due to inadequate medical care.⁴⁵ Moreover, incarcerated pregnant women are routinely shackled during labor and childbirth and separated from their newborns shortly after giving birth, which prevents them from breastfeeding and bonding with their babies and can subsequently lead to adverse medical outcomes for the moms and their babies.⁴⁶ The threat is particularly acute for incarcerated Black women, who are imprisoned at approximately two times the rate of white women.⁴⁷ It is essential that New Jersey' criminal legal system establish policies that meet the unique needs of incarcerated pregnant women, mothers, and the children/families they leave behind.

Criminal Justice's Primary Role: Provide care and support for incarcerated women and their babies; facilitate successful re-entry into society

Within New Jersey, there are currently approximately 700 women who are incarcerated.⁴⁸ Other women have been placed in different diversionary programs such as halfway houses. Edna Mahan is the sole women-only corrections facility in New Jersey. This facility has an extensive mother-child program which has been in existence for more than 20 years and has an annual Christmas Party, where children receive several gifts. Edna Mahan also has child-friendly visitation rooms, with child-sized chairs and books in the minimum and maximum security units. The visiting hours are determined by which compound the inmate is currently in; up to three adults can visit at a time, no more than six total visitors including children. Medical services are handled by Rutgers under the direction of the Department of Corrections (DOC). DOC ensures that a woman has someone with her to help with delivery and works with the Department of Children and Families to have a child placed after birth. However, data show that a child and mother both fare better when the mother can nurse and bond with the child prior to separation.⁴⁹

Top Collaborator Candidates: Academia, business, private funders, health, public sector and community/grassroots organizations and food systems.

Incarcerated pregnant women represent an extremely vulnerable population; most often they are overlooked and not considered. Incarcerated pregnant women are more likely to have substance use disorders, be of a lower socioeconomic status, and have a history of trauma and/or abuse, leading to worse perinatal outcomes than nonincarcerated pregnant women. ⁵⁰ Within New Jersey, the Department is making great strides in caring for pregnant women, but more should and can be done to create a supportive environment for incarcerated mothers to have safer births. Academia/workforce development, business, private funders, and community and grassroots organizations could work together to provide social support for moms before, during and after pregnancy.

Areas for Criminal Justice to Innovate and Collaborate:

PROJECT	Academia	Private Funders	State Agencies	Community / Grassroots Organizations	Service Providers – Criminal Justice
Private funders and the public sector could work to develop and provide training for correctional officers and medical personnel to ensure that pregnant incarcerated women receive care that promotes their health and safety	Partner		Co-lead	Partner	Lead
Work with community/grassroots organizations, academia, and health to provide counseling and treatment for pregnant and postpartum individuals with substance use disorders, mental health conditions, and chronic conditions	Partner	Partner	Partner	Partner	Lead
Business/workforce development, academia, private funders, health and the public sector can work together to provide reentry assistance, including access to social services that will ensure the holistic health of the mother and her child		Partner	Partner	Partner	Lead

PROJECT	Academia	Private Funders	State Agencies	Community / Grassroots Organizations	Service Providers – Criminal Justice
Pregnancy and childbirth education for all incarcerated mothers could be provided through doulas/midwife support provided and funded by academia/workforce development, public sector, health, and private funders					Lead

Community and Grassroots organizations

Overview

Community and grassroots organizations have their finger on the pulse of the communities they serve and could be a conduit for delivering services as well as determining what mothers and infants need within cities/townships with high maternal and infant mortality and morbidity. These organizations have undergone the time-intensive work to build trust with community members and have a shared vision of addressing social and health equity issues.

Community and Grassroots Organizations' Primary Role: Embed in communities; advocate for a rally around policy to improve social services needed to support safer birth

Community and grassroots organizations embedded in the communities and cultural networks most hard hit by maternal and infant mortality and morbidity must be leading the change outlined in this Plan, including 100 Black Lives, NAACP and Melinated Moms. Organizations such as Camden Coalition are working to improve health care for women with complex health and social needs in Camden through partnership with community organizations to monitor and treat complex chronic disease before a woman gets pregnant, during her pregnancy, and after she gives birth, using a model called interconception care.⁵¹

Top Collaborator Candidates: All sectors

This sector is the most versatile and able to work across all sectors described previously. Beyond health, this sector is the next in importance as without community input, interventions will not succeed. Nurture NJ ultimately will require the buy-in of mothers and organizations/individuals across all sectors described above. Community and grassroots organizations can facilitate this relationship by providing safe spaces for people to meet and engage and to serve as a conduit for multi-sectoral activities.

Areas for Community/Grassroots Organizations to Innovate and Collaborate

- Collaborate with other like-minded organizations to have a greater impact within the communities that they serve
- Lead all the other sectors to develop and advocate for local and state level polices that address food insecurity, environmental hazards, transportation access issues, and housing instability
- Work with businesses and private funders to increase funding to community service/grassroots
 organizations addressing maternal and infant mortality and morbidity.

Conclusion

Multisectoral engagement will only succeed if all stakeholders share the same vision and perspective, and practice health equity impact assessment in all policies and practices relevant to mothers and infants. Each sector will need a champion who is prepared, dynamic, and can understand the system and communicate effectively. It is important to have collaborations where the outcomes are measurable and demonstrate that Nurture NJ has met its goal of reducing maternal mortality by 50 percent over five years and has eliminated racial disparities in birth outcomes for all New Jersey moms. If the sectors can find the common goals to rally around, Nurture NJ's success is inevitable.

Section III. Equity Evaluation for Nurture New Jersey's Maternal and Infant Health Strategic Plan

Pauline E. Brooks & Patricia H. Karimi-Taleghani

Human rights, health justice, human centeredness, and equity are values that frame this evaluation plan. In the search/aim for equity, inequities must be addressed. By definition, racism, sexism, classism, heterosexism, ableism, and the like are inequitable: hence, this evaluation plan is designed to be antiracist, anti-sexist, anti-classist, anti-heterosexist, anti-ableist, and the like in its approach to racial and other disparities. This evaluation plan also prioritizes underserved/marginalized families and communities. In particular, it seeks to identify and measure selected health, equity, and ecosystem (contextual) processes and structures that advance and/or hinder quality health care treatment and outcomes for underserved/marginalized New Jersey mothers and their babies. Underserved and marginalized includes communities that have historically been harmed, excluded, and/or neglected based on race, ethnicity, culture, low-income and no-income, ability, sexual orientation, geographical location, or similar other characteristics. Consistent with the First Lady's focus, one key emphasis of both Nurture NJ and this evaluation plan is a focus on reducing/eliminating long-persisting racial disparities between New Jersey's Black maternal and infant death and morbidity and white maternal and infant death and morbidity.

The evaluation will draw from relevant existing instruments and data. It will also create new instruments and data. The evaluation methods will be multiple and adaptable, as required by the breadth, size, and focus of the Nurture NJ Strategic Plan and current unprecedented state and national circumstances (e.g., COVID-19 (SARS-CoV-2) pandemic and demands for racial and social justice taking place in streets across the nation, etc.). Measures selected will depend on the best fit given the historical contexts, immediate needs for flexibility and adaptability, and the nature of the topic being assessed (e.g., maternal and infant death and morbidity are highly sensitive topics, especially for affected families and communities). Data variety and mixed methods used by evaluators may include, but not be limited to: quantitative data, qualitative data, surveys and questionnaires, interviews, participant observations, prioritizing and sorting techniques, photographs and video documentation, document reviews, phone, email, social media or other internet data gathering.

One part of the Nurture NJ plan is statewide. Evaluation concerning this part of Nurture NJ will involve assessments of large institutions/agencies and some portions of the business and private sector. In terms of the large institutions/agencies, the evaluation will have a major focus on how structures, policies, and practices of these institutions impact maternal and infant health in New Jersey, especially racial disparities in health. There will be focus on how this infrastructure is modified over time (changes in any structures, practices, and inter-institutional collaborations) in efforts to reduce/eliminate maternal and infant racial and class (low-income and no-income) health disparities. Evaluators will also collect data about Nurture NJ's engagement with the business and private sector. Some of that data will pertain to the racial healing trainings that are planned for statewide actors, agencies, and the business and private sector. Assessment of Nurture NJ's public messaging will be another area for evaluation focus.

A second large part of the Nurture NJ effort focuses on processes, policies, and outcomes affecting specific communities in New Jersey. This is Nurture NJ's place-based strategy. Once Nurture NJ has selected the place-based communities (communities that participate most directly in Nurture NJ programs), evaluators will collect a variety of baseline data about place-based and non-place-based communities (i.e., comparison communities). The methods and processes for selecting place-based communities are not yet developed and should be done so with the collaboration of community.

Evaluators will also seek insights from professions not commonly included in mainstream health discussions of racial and other disparities in health. This may include midwives, doulas, community workers, peer counselors, social workers, curanderas, dentists, mental health workers, substance abuse counselors, medical professionals who provide health services in prisons and jails, and others, and research methodologies.¹

In parallel, there will be key variables followed over time at the level of underserved/marginalized New Jersey communities (place-based and non-place based). This is part of Nurture NJ's community engagement effort. Here, a main emphasis will be on community health and empowerment. Evaluators will assess changes (e.g., organizing, gaining and sharing knowledge, partnering/engaging with health and other authorities, etc.) that happen in underserved communities focused on addressing racial and other disparities in health.

Evaluators, too, will function in ways that move toward equity: evaluators will include, work with, train and employ knowledgeable members from communities most impacted and harmed by New Jersey's maternal and infant racial and other disparities. To do quality work, evaluators will need the knowledge and insights of community members, especially given that such voices historically have yet to be included in vital discussions, analyses, proposed solutions, planning, and evaluations that impact their communities. Also different from evaluation-as-usual, evaluators will need to budget appropriately and adequately for communities to participate in many important ways, including as evaluation team members. Proper budgeting for community participation is often missing.

Special Challenges for the Evaluation: Societal Uncertainties and Sensitive Issues

Societal uncertainties. As of this writing there are large-scale uncertainties contemporaneous to Nurture NJ. These can potentially influence the evaluation. A few are: a racially disparate COVID-19 pandemic; community lock-downs and rule changes involving social distancing; nationwide demonstrations in support of Black Lives Matter (and against police violence and the police killing of Mr. George Floyd and others); demonstrations demanding racial equity, justice, and increased social services; high unemployment, coupled with dramatically shrinking income and health coverage; shortages in housing; and major disruptions in access to non-COVID healthcare, and family households.

Sensitive issues. Evaluators always have a responsibility to handle sensitive topics in special ways. The outsized deaths and morbidity of Black mothers and their babies compared to white mothers and their babies in New Jersey (and nationwide) is a doubly sensitive issue: One aspect of sensitivity involves all of the emotions, upset, shock, depression, and other stresses that occur when a family is dealing with the death or morbidity of a loved one, especially a new mother or infant. A second aspect of sensitivity is

the enormity of the racial disparities and *unnecessary* deaths and morbidity that have persisted over decades (see Section 1.3 of this document).

Evaluating sensitive and emotionally charged topics like those addressed by Nurture NJ requires that evaluators open further and stretch their own humanity. Especially for this kind of assignment, members of the evaluation team have to have well-developed empathy, honesty, trustworthiness, and cultural/racial/class sensitivity, etc. Evaluators will be working with interviews, case studies, and other types of data with families and communities where New Jersey's moms and babies disproportionately die or are ill, sometimes from easily preventable causes including racism. At some point, evaluators may be coming into contact with deeply felt loss, pain, depression, mental and emotional stress, grief, and other upset on the part of persons from whom they will be asking permission to collect data.

Another sensitivity involves trust. There are valid historical and contemporary reasons for members of underserved and marginalized communities to not hold much trust in evaluators or other authorities: from the perspectives of underserved/marginalized communities, current mainstream structures and arrangements are responsible for creating and/or maintaining the disparities in the first place. Additionally, in the past, evaluation-as-usual has often brought more harm than benefit to underserved racial, cultural, and low-income/no income communities. Given these kinds of historical forces, evaluators will have to earn trust. Community members will be watching how evaluators enter and interact with and within communities. Evaluators will have to be very conscious about operating in ways that are ethical, truthful, transparent, culturally and historically appropriate, and reciprocal, as understood and seen through the eyes of the community. Without this, data gathered by the evaluation team will be weak at best, and inaccurate at worst.

Evaluators will need to go places where they traditionally have not gone: comparing racial disparities (particularly Black compared to white) and class disparities (lower-income and no-income compared to higher incomes), and the intersections, with the intention of documenting and providing insight into how to eliminate the disparities. Dating back centuries, these disparities are connected to deeply rooted, intentionally-structured, historical systems of racial and class hierarchies. Nurture NJ evaluators will find themselves facing and needing to address issues like:

- Existing manifestations of racism, classism, and sexism: institutionalized, structural, procedural, personal, etc. deeply involved in the health disparities
- Needing to expand the sources of information and evaluation data to include people from underserved/marginalized communities, and other health-related professions
- The sharing of women's personal experiences with pregnancy, labor, delivery, post-partum, especially the experiences of women of color (including upper class and/or educated Black women), and women who are low-income/no-income, rural, un-housed, immigrants, challenged with substance abuse, imprisonment, unwanted pregnancy, needs for birth control, etc., and other women. Even when mother and infant return home alive, these families may have experiences of harm, neglect, disrespect, etc.

In sum, the evaluation team for Nurture NJ must have solid "people skills." It will also need high technical skills and ethics to be effective in working across such a wide range of sensitive topics and trust

issues, unprecedented circumstances, disparate racial and class contexts, and a variety of data collection methods.

EVALUATION QUESTIONS

The following evaluation questions are intentionally broad. This is in order to fit the broadness and scope of Nurture NJ's Ecosystem model of transformation.

Because the Nurture NJ Strategic Plan represents a relatively new approach and engages such large and diverse aspects of society, one level of the evaluation is simple *discovery*.

EVALUATION QUESTION #1: (Baseline) What are the nature, contexts and outcomes, including racial equity and racial class, and other disparities concerning maternal and infant health in New Jersey? If at all, how do these change over time (e.g., what are the outcomes of place-based compared to non-place-based)? When changes do occur, which changes are structural (relatively permanent) as opposed to temporary changes (e.g., short-term changes, programs for which funding is discretionary or expires in a few years, etc.)?

Evaluation Goal A: Develop a Deep and Inclusive Baseline. Part of the data for baseline (data that describe the situation at the beginning before any attempts to change the situation) will be from various New Jersey institutions and departments (e.g., New Jersey Transportation Department, Education Department, Health, etc.). These evaluation baseline data will describe how the policies and actions of institutions and departments potentially influence racial, class, gender, and other disadvantaged New Jersey groups. Evaluators will need to develop some type of equity assessment of the direct and/or indirect impacts these institutions and departments have on the health outcomes including disparities for mothers and infants/children. What roles do or can these institutions play in efforts to move New Jersey toward becoming the safest place to give birth? As mentioned, there will also be racial equity trainings for institutions and the business and private sector. Evaluators will need to collect data about the effectiveness of these trainings: Over time, did anything meaningful change as a result of these trainings concerning racial equity and other disparities?

Since the health sector is directly related to health disparities, evaluators will explore this sector far more deeply. Evaluators will collect various data on racial and other disparities in treatment and outcomes, hospital and other medical policies (e.g., Medicaid payer system) and practices, patients' experiences of racism, etc. especially concerning mothers and infants/children. There will be a clear focus on how to reduce/eliminate the enormous persisting racial and other disparities in maternal and infant mortality and morbidity in New Jersey.

Sensitivities working with the New Jersey health data. Table 1 illustrates one small part of the racial disparities reflected in New Jersey's health data. Data in Table 1 are illustrative of what is meant here in this evaluation plan as deep baseline data. The table shows persistent racial disparities in New Jersey's infant mortality. These are among the disparities that Nurture NJ seeks to reduce/eliminate. Notice that Black infants have been dying in New Jersey at roughly three to almost five times the rate of white infants over an extended period of time (there are data that go back many decades). This pattern is important. Notice also the increased numbers of Hispanic infant deaths compared to whites, and Asians

compared to whites. These and similar patterns too are important. Part of the deep baseline that the evaluation team will need to construct also includes Indigenous and other racial/ethnic populations, other underserved/marginalized populations, and lower-income and rural white New Jersey communities.

Notice the last line of Table 1: this line means that authorities even *plan to continue to maintain racial disparities* in that their targets (what authorities are aiming to achieve) are racial disparities. Whether intentional or not, one of the targets aimed for in Table 1 is 6 Black infants dying for every 1.9 white infants. Consider for a moment: If the proposed plan was for 6 white babies dying for every 1.9 Black babies dying, persons in authority would have thought this to be a crime and would have taken steps immediately to right this wrong. The "Target" line in Table 1 exemplifies how society's unequal treatment of some groups of people becomes so normalized and institutionalized that it passes unnoticed (see separate paper on *Racism and Racial Disparities* among the background papers in the Nurture NJ Strategic Plan—evaluators should review that paper for other examples related to New Jersey). Nurture NJ evaluators will need to closely examine infant and maternal mortality and morbidity data and other health and related data for all forms of such normalized racism, classism, and other -isms that function to create and/or maintain disparities.

In the three tables that follow, Black infants and Black mothers experience disproportionately higher incidences of death compared to other racial groups, especially whites. Indications are that these racial disparities are even worsening in recent years. Such comparisons are a critical part of the evaluation: comparisons need to be plotted (consider plots of data that cover 50-60 years) to see the trajectories over time, as well as to see if there are any decreases in racial disparities as a result of Nurture NJ efforts.

Table 1. New Jersey Infant Deaths Per 1,000 Births by Race, 2010-2017²

YEAR	BLACK	ALL	HISPANIC	ASIAN	WHITE
2010	11.4	4.8	4.3	3.6	2.6
2011	10.8	5	4.4	3.8	3.1
2012	8.7	4.4	4.2	3.2	3
2013	10.6	4.5	4	3	2.6
2014	8.7	4.4	4.7	1.9	2.6
2015	9.7	4.8	4.6	2	3
2016	10	4.1	3.7	2.6	2.2
2017	9.4	4.5	4.8	3.2	2.7
TARGET	6	3.7	3.3	1.8	1.9

See healthdata-nj.gov/database/INFANT-DEATH-RATE (No Page Numbers) Accessed 1/17/20

Table 1 developed by Patricia Karimi-Taleghani

Table 2. New Jersey Maternal Death by Race/Ethnicity, 2009-2013 (Per 100,000 live births)³

New Jersey racial maternal deaths are not proportional to their respective percent of the New Jersey population. Based on New Jersey state health department data accessed 2/7/20, estimated New Jersey population percentages for the four main racial groups are:

Black (12.8%)

White

(54.6%)

Hispanic (20.6%)

Asian

(9.7%)

Though the Black population comprises only 12.8 percent of the overall population of New Jersey, Black mothers are 46.2 percent of pregnancy related deaths, and 38 percent of non-pregnancy related deaths; whites in NJ comprise 54.6 percent of the general population, but white mothers are 26.9 percent of pregnancy related deaths, and 48.8 percent of non-pregnancy related deaths.

RACE/ETHNICITY	Pregnancy-Related N (%)	Not Pregnancy-Related N (%)
	N=78	N=129
BLACK (Non-Hispanic)	36 (46.2%)	49 (38.0%)
WHITE (Non-Hispanic)	21 (26.9%)	63 (48.8%)
HISPANIC	12 (15.4%)	12 (9.3%)
ASIAN	6 (7.7%)	4
OTHER	3	1

Table 3. US Pregnancy-Related Mortality by Race, 2007-2016⁴

	PREGNANCY-RELATED MORTALITY BY RACE/ETHNICITY, US 2007-2016[1]					
	Per 100,000 live births					
YEAR	Black	American Indian/Alaskan Native	White	Hispanic	Asian/Pacific Islander	ALL
2007- 2008	35.6	26.9	11.5	10.8	11.4	15.0

2009- 2010	41.6	30.7	12.8	12.8	13.6	17.3
2011- 2012	44.3	38.4	12.4	10.4	11.6	16.8
2013- 2014	42.1	30.3	13.5	12.0	15.8	17.6
2015- 2016	40.8	21.9	13.2	11.6	14.7	17.0

Table 3 developed by Patricia Karimi-Taleghani

Nationwide numbers of maternal death by race are not much better (Table 3). The deep baseline may sometime need to consider national statistics for comparison with New Jersey statistics, as represented by Table 3.

Evaluation data are to be disaggregated by race, class, gender, rural-urban-suburban, age, etc. Intersections of these data, too, need to be examined.

Contextual data. The evaluation team's construction of a deep baseline will need to include data on factors that influence maternal and infant health. This may include such things as: availability of affordable and nutritious food, safety, health insurance, availability and distance of health services, access to transportation to and from healthcare, etc. Given the history of the US, complications for evaluators will include things like:

- 1. The normalization of inaccurate racial assumptions, biases, prejudices
- 2. The prevalence of racial/cultural mis-information, mis-education, and absence of knowledge about underserved/marginalized populations
- 3. The domination of one racial group's (Eurocentric) perspective-taking and narratives
- 4. The extent to which narratives and actions concerning race, class, gender, geography, ability, sexual orientation, un-housed, etc. are rooted in hierarchical relationships—and not in equality among all people
- 5. The effects of centuries-long structured and intentional unequal treatment and second-class status for ethnic groups of Color as normalized and routine
- 6. Society's long history of neglecting the needs of underserved populations
- 7. Historical practices of omitting explorations of racism, racial history, racial segregation (*de jure* and *de facto*), when working on issues involving people of Color

Budgets. Budgets are moral documents. They are statements about what is valued. Budgets also tell where power lies. Among other things, Nurture NJ seeks to uplift the valuing and prioritizing of New Jersey's mothers and their babies, especially those that have been long marginalized. As such, evaluators need to examine the budgets for proposed Nurture NJ programs and projects: e.g., Do the various Nurture NJ budgets include monies for meaningful strategies for underserved-community input?

Are budget amounts line items (more permanent) or discretionary? What is equitable about the Nurture NJ budgets?

Why should the Nurture NJ evaluation be concerned with the foregoing kinds of issues? A brief example: the New Jersey Health Department lists on its website the following as "factors contributing to adverse outcomes" for mothers and infants: "nutrition, quality of prenatal care, medical problems, infections, use of cigarettes, alcohol, and other substances, mother's age, obesity, stress, violence, and poverty". ⁵

Yet, nothing on this list from the New Jersey Health Department mentions the impacts of historical and present day systemic, institutional, or personally-mediated racism, racial prejudice, racial discrimination, racial segregation, procedural racism, the intersection of race and class, racism in the budgeting and allocation of resources, services and opportunities, mistrust, cultural misunderstandings and misinformation, fears, etc. When the Nurture NJ strategic planning team held community dialogues in March 2020 on the topics of pregnancy, childbirth, and healthcare in New Jersey, two discussion groups of mostly Black and Brown women/mothers in South New Jersey brought up the following as *their* concerns about their and their babies' health and well-being:

[Paraphrased] no supermarkets, no dentists, no mental/emotional health centers in the city; multiple incidences of disrespect, disregard, lack of professionalism, even abusive and possibly illegal behavior on the part of medical staff as experienced by Black and Brown women during prenatal check-ups and delivery; such "bad" experiences made women not want to return to these medical institutions; stress merely from just trying to make a medical appointment, or from medical staff being careless about what they say in front of People of Color; medical staff not listening, not believing, and not medically investigating women's complaints of pain or that something doesn't feel right, which among many other things undermines trust; not being free to speak up because White medical staff feel threatened by a Black woman speaking up—in turn, this instills fear in the patient of Color in that medical staff have ways to retaliate; medical staff are sometimes not prepared, and may not speak with one another in order to be informed about the patient; based on the behavior of medical staff, some patients of Color feel that they do not receive care that is attentive, and that some of the medical staff do not really care; medical staff not taking time to communicate with patients, but rushing through appointments; rudeness; medical staff clearly giving priority to privately insured patients over those with Medicaid; stigmatizing Medicaid; women not knowing who to call when they have medicallyrelated questions; women having a different doctor each time they go in for medical treatment, which limits any relationship/continuity building; etc.

What these women name as impacting their and their babies' health and well-being generally does not appear in mainstream discussions and analyses by largely white authorities. What Black and Brown New Jersey mothers described in March 2020 is not well-represented in the content listed on New Jersey Health Department's website. The issues of mothers of Color need to be valued. These mothers and families need to be centered, heard, and taken seriously by New Jersey decision-makers. Evaluators have to be aware of (and give feedback on) these kinds of holes in shared knowledge. The evaluation team will also have to capture changes generated by Nurture NJ efforts to address these issues raised by

underserved mothers: e.g. What attention is given to things described by Black, Brown, low-income/no-income, etc. New Jersey mothers? What real resources, opportunities, services, and/or re-balancing of power happens for underserved women as a result of Nurture NJ efforts?

Evaluation Goal B: A few equity evaluation models and frameworks

Nurture NJ evaluators are encouraged to thoroughly scrutinize the "Toolbox" that accompanies the Nurture NJ Strategic Plan. It has a variety of tools, including tools for the Racial Healing training of Nurture NJ. Several additional evaluation tools/approaches/frameworks are briefly discussed here. These deal with equity, racism, and other societal inequities, and context.

1. Equity. Equity can manifest in: ideas, concepts, words, narratives, values, intentions, goals, behavior, relationship building, procedures, cultural ways, policy, structure, systems, ideology. Inequities (such as racism, sexism, etc.) can exist and/or be reflected in these same things. Equity and inequity are two sides of the same coin. 7,8

IN PRACTICE BASED ON MODEL 1

Equity	<u>In</u> equity
Building and supporting equity	 Building and supporting <u>in</u>equity
Interrupting things that dismantle equity	 Interrupting things that build and support equity

Equity can be facilitated through direct actions (e.g., intentionally building/inserting equity into policies, or dismantling inequities, etc.) and indirect actions (e.g., training people on the value of equity or how to spot inequities). Not taking action concerning equity or inequity means acceptance or support of what currently exists, i.e., the status quo of disparities.

2. Racism and other societal inequities. Evaluators can use various frameworks and strategies for different aspects of Nurture NJ efforts. Several include:

R4P. The R4P framework "operationalizes assessment of the context of racism, insittutionalized factors, intersection of race, class and gender, as well as the temporal dimensions impacting on lifecourse and intergenerational effects."

- Remediation of existing, known contributors to inequities and the repairing of historic contributors to current risk;
- Restructuring of currently patterned sources of risk in policy or programming for populations of color;
- Removing sources of structural racism and addressing specific needs created by the intersection of race, class, and gender;
- Repairing the damage of historical occurrences of discrimination; and
- Providing services that were culturally and economically relevant to the populations served.

REPAIR

Historical risk and its embodiment in current physiologic, biologic, psychological and social effects (e.g. repair the damage of the past)

RESTRUCTURE

Structural changes (social, economic, educational, rules, regulations, etc.) to stop new production of risk

PROVIDE

Culturally and economically feasible health education and medical care with the requisite structural support so that people choose and can sustain health behaviors.

Remove power imbalances, racism and inequities in socio-economic status

Reduce or buffer exposures and reduce vulnerability; reduce unequal consequences of existing inequitable structures and functions

R4P Framework: see Appendix 4 for more details regarding R4P.

The *BET (Brooks Equity Typology)* is an interdisciplinary research, evaluation, program, and/or policy tool—like a kind of map—for identifying places and activities within society where inequities have historically occurred. The *BET* has nine major categories: 1. Power and Authority; 2. Rules; 3. Actions/Emotions; 4. Ideology/Thinking; 5. Systems and Institutions; 6. Environment (Physical Environment and Social Environment); 7. Developmental/Lifespan Human Development; 8. Resources and Services; and 9. Legacy/Historical Accumulations. Each of these nine categories has subcategories from which one can select to explore for specific aspects or issues of equity or inequity (e.g., racial equity, gender equity, class equity, etc.). Subcategories can be adapted as needed and there are places to insert one's own original subcategories or emphases. (See Appendix for more details.)

Another instrument involves a way of categorizing organizations based on the descriptions of what those organizations do and do not do in terms of equity.¹¹

3. Context. Context gives meaning to things: the same behavior may have different meanings given different contexts. Everything happens in a context.⁷

Example concerning context. In a multi-year study, when newly delivered Black women said that they ate lots of vegetables, white researchers assumed/interpreted via "cultural layering" that these vegetables were the same type and quality of vegetables that appear in supermarkets in white areas of the city. Black community members on the evaluation team corrected this assumption: They demonstrated that in the Black communities in which these women lived, "fresh" vegetables were the rejects from the same supermarket chains that sold truly fresh vegetables in white communities. In fact, the majority of vegetables and fruits available to Black community members were canned (with added salt, preservatives, food coloring, and sugars, etc.). ¹² Throughout, the Black community members of the evaluation team improved the knowledge, validity, and accuracy of the work.

5-Paths Analyses fits with the Ecosystem model of Nurture NJ in that it provides a way to look more deeply into racism, other inequities, and contexts. It is important for communities to be involved in identifying key issues, community histories, stories, and points of view. 5-Paths is a strategy for accessing community voices and digging into context.¹³

1. HISTORY and CULTURE

Plot relevant disparities statistics for race and class over multiple decades. Examine trends. For example, consider questions such as:

- What has been the history of the underserved/marginalized (racial and lower-income/no-income) communities/populations within the larger society?
- What previous efforts have there been to reduce/eliminate disparities and by whom? When? Where? Under what conditions?
- How were problems of disparities framed? For example: were disparities thought of as resulting from some shortcomings in the behavior of Black and lower-income people?
- What efforts worked, and what efforts did not? Why?
- What did family members who have lost a mother or infant say about what actually happened and why it happened?

2. LATERALITY

Disparities take place within a surrounding context, i.e., an ecosystem. In that ecosystem, what factors serve in ways to re-create, sustain, or change these disparities? If these racial and class disparities were to instantly disappear, what would be forced to change as a result? For persons invested in the status quo, what motivation or incentives or reward system are there for persons to change the status quo (and perhaps their position, status, income, career opportunities, etc.)?

3. ACCUMULATIONS

What other relevant problems have been created or accumulated over the many decades as a result of racial and class disparities in maternal and infant mortality and morbidity? Are there new or exacerbated debts or financial needs, depression, hunger, homelessness, substance abuse, spiritual or mental health issues, etc.?

4. RESISTANCE/OBSTACLES TO REDUCING DISPARITIES

In past efforts to reduce disparities, what has resisted or been an obstacle to change? How were these resistances addressed, and with what effects/outcomes? What are contemporary resistances to changing the status quo concerning these disparities? Resistance may be disguised as something else: e.g., not enough money, needing more research on the problem, not prioritizing the problem or proposed solutions, minimizing the significance of the issue, not placing the issue on the agenda, or as last on the agenda, no time, etc.

5. POWER

Who makes key decisions that have important bearing on specific disparities? Who defines the problems, gives priorities to these problems, controls the resources, determines who is included in identifying and defining the problems, proposes solutions, and decides what to do about the problem, when, how, and by whom, etc.? This also asks the question: To what extent and how do persons negatively affected by racial and class disparities have power in decisions about their community? What is the balance of power? Is that balance equitable?

EVALUATION QUESTION #2: What parts of the ecosystem model of transformation are implemented (e.g., at the level of state and other institutions, business and private sector, underserved communities, etc.)? How are these implementations impacting the health, health treatment, care, and outcomes of New Jersey's mothers and infants, especially in terms of disparities? In what ways are specific implementations impacting mindsets, ideology, and research about women, people of color, low-income/no income, and other underserved persons? How do implementations impact racial, class, and other disparities in non-health sectors such as in employment, income, asset building, housing, education, safety, investments in communities, etc.?

Evaluation Goal C: Drawing from the Nurture NJ Ecosystem Map

Evaluators will document how Nurture NJ participants are using and designing their implementations based on the Ecosystem Map. Achievement of the expected outcomes is highly dependent on building as much of the Ecosystem as possible in New Jersey.

Evaluation Goal D: Preparations for identifying intended and non-intended changes/transformations

Evaluators will need to be clear about what planners and implementers see as important planned changes/transformations. A separate document of indicators/end goals (see "Selected End Goals as Identified by the Nurture NJ Strategic Planners," August 5, 2020) and different sections within this present paper point to desired changes. Further, evaluators will need to determine other indicators given that this Nurture NJ Ecosystem model has many parts.

Evaluators will need to identify and gain access to relevant data that are already routinely collected concerning New Jersey's disparities. This will take time. Evaluators will need to work with how data categories are defined and frequency of data collection across different agencies: e.g., the nature and format of the data, units of measure, accessibility, interagency compatibility, etc. There will also be relevant data that are not presently being collected, processed in a timely fashion, or otherwise available. For instance, specific relevant data on the many different New Jersey racial communities, Indigenous communities, LGBTQIA+, rural, and lower-income, no-income communities may not exist, or not be current, flexible, or easily accessed. The intersections of disadvantages (e.g., race X income level X rural) need to be included; they are often absent, yet important for the Nurture NJ effort. Expect some problems with New Jersey's health disparities data.

Evaluators will have to develop and implement mechanisms (instruments, knowledgeable staff, training of evaluation staff, setting a timing plan for data collection, etc.) for acquiring the needed existing and not-yet-existing data. This evaluation includes training of eligible people from local New Jersey

communities (racial, Indigenous, LGBTQIA+, rural, and/or lower-income, or no-income communities) to have meaningful roles on the evaluation team. This supports community engagement, one of Nurture NJ's values. It is an equity principle as well as a cultural value within many underserved communities: include communities and always leave something behind of value in communities, not just extract.

Training and education are bi-directional: Evaluators will need to learn from community members: e.g., what to ask, how to ask it, when to not ask, how to best enter a particular community, what topics to not collect data on, etc. Also, to keep everyone safe and protected: a) do not ask about place of birth, first language, immigration status, or activities of the participant's neighbors; b) inform community participants that you cannot guarantee complete confidentiality because of the Patriot Act (the Federal Government can take all of your data, computer, etc. and it is against the law for you to tell anyone about the seizure); c) build in other safety precautions (e.g., double coding of any potential or personal data); d) be very careful to spend time making sure that each community participant is well informed about her/his rights; and e) obtain written permission (informed consent) early and for at least one year at a time in order to be able to re-contact participating community members.

All of the preceding require that additional time is built into the evaluation. This time is an investment in the overall quality of the evaluation.

Evaluation Goal D: What the evaluation will investigate and measure at the Level of the Governor's Office

To what extent has the Governor's Office and Office of the First Lady set the stage for a new culture of equity in New Jersey?

At the Level of Departments (e.g., New Jersey Transportation Department, Education, Health, Social Services, etc.). Building and strengthening equity (equity meaning justice, fairness, equitable) is a major goal of the Nurture NJ plan. Evaluators will probe questions like:

To what extent do departmental structures, policies, and practices support, or not support equity, racial equity, gender equity, class equity, etc.? (Baseline)

After exposures to Nurture NJ's trainings on equity: what do departments do with this knowledge? What changes concerning departmental structures, policies, practices/implementation, etc. occur? If some things do change, what difference do these changes make concerning underserved/marginalized New Jersey populations? How and why did change occur or not occur?

What indications are there that people within major New Jersey institutions exhibit added or increased valuing of equity or any mindset changes as a result of racial healing- or other equity trainings?

Are there indications that equity is infused in how institutions, businesses, etc. develop and enforce policy and/or operate on a daily basis?

At the Level of State and Local Health Institutions. Concerning equity and health, health services, practices and resources, diverse topics for this evaluation may include but not be limited to:

Policies and common practices around women's health, pregnancy, birthing, postnatal care Myths, attitudes, and assumptions about women, and in particular women of Color and low- and no-income white women, LGBTQIA+, etc.

Diverse cultural ways and practices of marginalized women concerning their health Historical and contemporary concerns of marginalized women about their health What marginalized women experience in their interactions with New Jersey's health institutions

Failures in cross-cultural communication, reading cross-cultural cues, and minimizing racism, classism and sexism, etc. in the medical setting

Authorities' listening to, responding to, and following through on, responses and commitments to underserved communities in ways that are timely and appropriate

During the present COVID-19 pandemic and its highly disproportionate negative impacts on the physical (sickness and death) and emotional health (stress) of Blacks, Hispanics, and lower-income and no-income people, how are medical institutions and facilities stepping forward to adequately, appropriately, and equitably address racial disparities, especially pregnant women of Color?

Women of Color's effective access to redress for faulty, disrespectful, unethical or neglectful medical care—what is the current enforcement for medically related transgressions, and/or what needs to be changed to make deterrents effective? What prevents such negative behaviors on the part of medical personnel in the first place?

Significant ways that various health institutions may be currently working with underserved women as successful partners in shaping services for the underserved

Health institutions envisioning working in the future with underserved women as partners in shaping effective services for the underserved

Monitoring and evaluating changes in health-related racial disparities data and statistics

Efforts to change or create new programs/practices (e.g., PFRC—Patient and Family Engaged Care) for improving services to underserved women and infants and families

Consciously and intentionally creating opportunities for careers/employment in the health field for members of underserved communities

EVALUATION QUESTION #3: What is the evidence that the implementation of the Ecosystem model of transformation and its emphasis on equity create any re-distribution of power and/or influence on behalf of historically disadvantaged New Jersey communities (community power-building)? To what extent are these communities sharing in decision-making, accessing needed resources, etc.? If mechanisms for shared decision-making with authorities are created, how sustainable are they? Are they line items in budgets? What other community organizing, and efforts emerge, take root, and collaborating on behalf of the community?

At the Level of Underserved Communities

From the beginning, evaluators will need to first work on showing respect for these communities, building relationships, and earning trust. The strongest situation is when the community extends an invitation to enter and to further build open and honest relationships.

One broad question concerning underserved communities involves: How is Nurture NJ working to engage underserved communities, including immigrant communities (and asylum seekers)? The evaluation will look at how Nurture NJ is reaching out to and serving the various underserved communities, and what comes from those efforts. Efforts may have short, medium, or long term (even intergenerational) effects on communities. Evaluators will explore questions like:

What equity-related opportunities are opened and benefit communities?

How are communities benefitting in other ways, if at all, from the existence of Nurture NJ?

Are avenues of dialogue and participation opened so that voices from these communities are heard?

What are the opportunities for people from these underserved communities to meet on equal footing with medical and other authorities to do collaborative work?

What is put into place to assure racially underserved women and other underserved women feel safe, cared for, well-informed about their treatments and any available services, and that they can trust the health care system?

What evidence is there, if any, that there is any shifting of power: e.g., power sharing or communities gaining an increased degree of self-determination over their health?

Is there employment, remuneration, or other Nurture NJ investment in these communities?

Other broad question concerns: What are levels and types of participation in Nurture NJ by members of underserved communities? Evaluators will seek insights into:

What are the real-life stories of mothers and babies in these underserved communities?

What is happening to people in these underserved New Jersey communities?

How are community members organizing to address equity and racial, class, and other disparities?

Is there participation in community trainings?

What is the diversity of community actors and institutions that are engaged (e.g., parishioners, teens, small business owners, etc.)?

Are there any goal-oriented shifts among community members or their institutions?

Are there inflection points demonstrating the voices of mothers and families in leading solution-driven advocacy, policies, etc.?

What, if any, is the participation of formal and informal leaders in power sharing?

In collaboration with communities—given that each community is different, and each has different circumstances, histories, and pre-existing advocacy efforts—evaluators can set up closer-to-realistic benchmarks/guideposts for agreed upon goals.

What are indications, if any, of community power building?

What evaluation questions do community members want answered about Nurture NJ efforts?

EVALUATION QUESTION #4: What are we learning (expected and unexpected) about doing things better for the health and well-being of underserved/marginalized communities for the next seven generations?

This is a question for different participating groups to answer at some future point in time. There is strength in leaving this question open-ended.

OTHER DETAILS

Budget— Same pay across specific positions: e.g., all ethnographers on the evaluation team (e.g., university graduate students and ethnographers from communities (their special knowledge is the community)) get the same rate of pay, benefits, healthcare, etc.

Timeline— Evaluators can begin immediately by identifying key health indicators about racial disparities in maternal and infant mortality and morbidity and related variables across all marginalized/underserved groups in New Jersey. This includes computing intersections and learning the deep context (e.g., use 5-Paths or something similar) to net a more holistic perspective.

Build added time into the budget. This additional time is needed for developing relationships and trust, developing and pilot testing instruments, conducting the deep and inclusive baseline, fully analyzing and interpreting the evaluation data in light of the history, culture, and context. Allocate time to learn from past approaches; people in the past—including people from these communities as well as authorities—have worked on these issues and have learned things. Time is also needed to learn about what is continuing to re-create and maintain present-day disparities: over time, follow any changes in these mechanisms for creating/maintaining disparities.

Evaluation Reporting— Major evaluation report every six months. Brief (2-4 page) report in between at three-month intervals.

In conclusion, creative new and older useful approaches are required. Even more important is developing and harnessing the <u>will</u> for moving toward more equitable systems, structures, practices, and behavior. As the Nurture NJ Ecosystem Map shows, this work requires fundamental mind shifts, and part of those mind shifts is the shifting of the <u>will</u>.



Appendix I

Glossary of Terms

TERM	DEFINITION
Acute Renal Failure	Acute kidney injury results in a rapid decrease in kidney function over days to weeks, causing an accumulation of toxins in the blood with or without reduction in amount of urine output.
Adult Respiratory Distress Syndrome	"Acute respiratory distress syndrome (ARDS) occurs when fluid builds up in the tiny, elastic air sacs (alveoli) in your lungs. The fluid keeps your lungs from filling with enough air, which means less oxygen reaches your bloodstream. This deprives your organs of the oxygen they need to function" (Mayo Clinic).
AIM-Alliance for Innovation on Maternal Health	AIM is a national data-driven maternal safety and quality improvement initiative based on proven implementation approaches to improving maternal safety and outcomes in the U.S. The end goal is to eliminate preventable maternal mortality and severe morbidity across the United States.
AIM Bundle	A bundle is a structured way of improving the processes of patient care and outcomes by using a straight forward set of evidence-based practices that, when performed collectively and reliably, have been proven to improve patient outcomes.
Cardiomyopathy	A primary disorder of the heart muscle, in which the muscle does not contract properly, leading to difficulty circulating blood to the body.
Community-based	Description of a project/activity likely to have a mix of community people and non-community people working together in a community; ideas and decision-making may include both community folk and non-community folk; has deeper roots in the community than place based.
Community-initiated	Description of a project or activity that originated from within a community, for the community, based on what the community identifies as priorities/needs.
Community-led	Description of a project or activity in which the community has power over decision-making.
Community-placed	Description of a project/activity likely to have a mix of community people and non-community people working together in a community; ideas and decision-making may include both community folk and non-community folk; has deeper roots in the community than place based.
Cultural racism	Toxic and stressful environments that stem from devaluing Black life and creating negative narratives around populations; the stereotypes that result trigger threat responses and white fragility which in turn lead to terrorism against African Americans. May limit access to needs/life desires because of threat of terrorism, e.g. "I don't go there because that is Klan country" Can also result in internalized racism.

TERM	DEFINITION
Disseminated Intravascular Coagulation	A condition in which proteins that control blood clotting become overactive causing small blood clots to develop throughout the bloodstream, blocking small blood vessels and causing excessive bleeding.
Doula	A para-professional support person trained in the needs of the pregnant woman and family during pregnancy and childbirth. The doula offers non-judgmental support, guidance, evidence-based education and practical hands-on support during childbirth including comfort measures.
Ecosystem	Nurture NJ uses the term Ecosystem to mean the deliberate and intentional interaction between society and its associated institutions (political, social, and economic) working in mutually supportive ways to create and sustain healthy and equitable human environments especially among those most harmed by racism and inequitable healthcare.
Ecosystem Map for Nurture NJ	An adaptive document used to guide HEIAP among all stakeholders committed to eliminating racial/class disparities in health and supporting excellent health and well-being outcomes. It includes three parts. Part 1 is the Abridged Version of the Strategic Plan. Part 2 is the Companion Document with detailed contextual information. Part 3 is a Playbook of tools and resources for implementing recommendations.
Embolism	A blockage of the blood supply in an artery caused by a blood clot or air.
Equity	Equity means justice, fairness, and given equal consideration. It is based on a fundamental principle that all human beings are intrinsically equal and should be treated as such.
Generative Conversations	Engaged dialogue in which individuals can construct and expand knowledge to develop action regarding critical contemporary problems. Generative conversations allow for discovery, shared inquiry, and new solutions. They activate collective action and focus to deliver results.
Health Disparities	 "Health disparities are preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations" (CDC). "Health disparities are the metric we use to measure progress toward achieving health equity. A reduction in health disparities (in absolute and relative terms) is evidence that we are moving toward greater health equity" (Dr. Paula Braverman).
Health Equity	The attainment of the highest level of health for all people. Achieving health equity requires valuing everyone equally with focused and ongoing societal efforts to address avoidable inequalities, historical and contemporary injustices, and the elimination of health and healthcare disparities.

TERM	DEFINITION
HEIAP Health Equity In All Policies	Also known as Health in All Policies (HiAP), is an approach that aims to integrate health considerations in decision making across different sectors that influence health, such as transportation, agriculture, land use, housing, public safety, and education. The phrase "health equity in all policies" is meant to suggest that considerations of equity be at the center of every policy. HEiAP emphasizes the need to collaborate across sectors to achieve common goals.
Hemorrhage/Postpartum Hemorrhage	Excessive bleeding (1,000 mL or greater) within the first 24 hours after birth but can occur up to 12 weeks postpartum.
Historical and Intergenerational Oppression	Factors that that lay the groundwork for all pathways of racism and set up the original hierarchy. Current social positionality is determined by this hierarchy.
Home Visiting	Home visitation programs are prevention programs that offer family-oriented services to pregnant mothers and families with newborns. Structured visits are made to the family's home. The visits may address positive parenting practices, nonviolent discipline techniques, child development, maternal and child health, available services, and advocacy.
Human-Centered Care	Health care providers placing human beings at the center of their practices and policies while seeking to produce racially just, equitable and civically responsible care as a "right" not a "privilege" for every person who resides within that society regardless of their citizenship status. Human Centered Care is, for example, physicians and other healthcare providers giving local realistic, culturally appropriate, high quality solutions to wellness challenges that face all humans and their communities whether access to healthy food, medicine (magnesium sulfate for pre-eclampsia, for instance, lowers the risk for a woman developing eclampsia), transportation, mental health services, housing, education, midwifery and doula services, breastfeeding services and equipment, as well as access to contraception and safe abortion services and quality post-abortion care.
Intersectionality	A framework for considering how differing aspects of an individual's identity such as race, class, ethnicity, sexuality, religion, immigration status, physical ability, education, rural/urban locality, age, un-housed, etc. combine to produce multiple overlapping and connecting forms of disadvantages and discrimination or unearned privileges and advantages.
Institutional Racism	Policies, procedures and practices that reduce access to the conditions of life that support health, e.g. access to jobs, health, housing, quality education; collateral consequences, toxic environmental exposures; disinvested neighborhood; biased and unequal access, care, treatment or prevention.
Maternal Death	The death of a woman while pregnant or within 42 days of termination of pregnancy, irrespective of the duration and site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management but not from accidental or incidental causes.

TERM	DEFINITION
Midwifery Model of Care	Midwifery focuses on the normalcy of pregnancy, and its potential for health. Birth is viewed as a natural process that has profound meaning to many people and should be treated as normal until there is evidence of a problem. Midwives are experts in protecting, supporting, and enhancing the normal physiology of labor, delivery, and breastfeeding. (JP Rooks, 1999)
Morbidity	Refers to disease or underlying disease symptoms; or the amount of disease within a population. Morbidity can also refer to health problems caused by a medical treatment.
Mortality	Is death; in medicine, mortality is used for frequency or death rate, as in the number of deaths in a certain population or group of people (of certain age, gender, race, ethnicity etc.) within a certain time period.
NTSV Surgical/Cesarean Birth	Surgical birth of Nulliparous (first time mother), Term (37 or more completed weeks of gestation), Singleton (one fetus) and Vertex (head-first presentation of the fetus).
Partnership	Is all stakeholders operating from a position of equally shared "power" dynamics, decision-making, and accountability within collaborative context(s). Nurture NJ partnership means cultivating and sustaining equitable institutional, psychological, and interpersonal behaviors that build on shared values, interests, and resources among institutions, individuals, and communities to foster positive and equitable outcomes through persistent effective communication.
Patient-Centered Care	Care that is respectful of and responsive to individual patient preferences, needs, and values and that ensures that patient values guide all clinical decisions. Patients are known as persons in context of their own social worlds, listened to, informed, respected, and involved in their care.
Preconception Care	A set of methodical, wide-ranging programs that identify and reduce women's reproductive risks before they become pregnant. It includes the care of women and men during their reproductive years, which are the years they can have a child. It focuses on taking steps now to protect the health of a baby they might have sometime in the future.
Preeclampsia /Eclampsia	Preeclampsia is new-onset or worsening of existing hypertension with leakage of protein into the urine after 20 weeks gestation. Eclampsia is unexplained generalized seizures in patients with preeclampsia.
Pregnancy- Associated Death	The death of a woman while the woman is pregnant, or within one year of the end of a pregnancy, regardless of the cause of death. These deaths make up the universe of maternal mortality; within that universe are pregnancy-related deaths and pregnancy-associated, but not related deaths.
Pregnancy- Associated but not -Related Death	The death of a woman during pregnancy or within one year of the end of a pregnancy, from a cause that is not related to pregnancy (e.g. a pregnant woman dies in an earthquake).

TERM	DEFINITION
Pregnancy-Related Death	The death of a woman during pregnancy or within one year of the end of a pregnancy from a pregnancy complication, a chain of events initiated by pregnancy, or the aggravation of an unrelated condition by the physiologic effects of pregnancy.
Procedural Racism	(From the field of law) Uses devices like cultural- and institutional rules to limit and invalidate opportunities for persons and groups previously identified as "inferiors." Delgado (1990) and Mohanty (1994, pp. 160-161) offer as examples that the law establishes difficult-to-meet requirements, including proof of intent, that makes it almost impossible to "prove" racism. Laws or programs may make it possible for a mother in poverty to get a job, but she then loses her childcare supplement. Without the childcare supplement she cannot work, yet the childcare supplement requires that she look for work.
Racism	The UNESCO (1978) definition of "Racism includes racist ideologies, prejudiced attitudes, discriminatory behaviour, structural arrangements and institutionalized practices resulting in racial inequality as well as the fallacious notion that discriminatory relations between groups are morally and scientifically justifiable; it is reflected in discriminatory provisions in legislation or regulations and discriminatory practices as well as in anti-social beliefs and acts; it hinders the development of its victims, perverts those who practice it, divides nations internally, impedes international co-operation and gives rise to political tensions between peoples; it is contrary to the fundamental principles of international law and, consequently, seriously disturbs international peace and security." []"Any theory which involves the claim that racial or ethnic groups are inherently superior or inferior, thus implying that some would be entitled to dominate or eliminate others, presumed to be inferior, or which bases value judgements on racial differentiation, has no scientific foundation and is contrary to the moral and ethical principles of humanity."
Reduction in Life Itself	Neglect/inaction of leaders in the face of need, e.g. extra-judicial killings, COVID-19 disparities.
Reimbursement for Human- Centered Care	A payment model which differs from a pay-per-service model in that it rewards compassionate, non-racist, equitable and high-quality healthcare to individuals and groups that have historically been neglected and/or harmed within the traditional pay-per-service reimbursement system. Physicians and other healthcare workers are reimbursed for valuing the total human being regardless of race, class, gender, or sexual identity/orientation and are rewarded for giving humane, local, high quality healthcare treatment for getting people well and keeping them well.

TERM	DEFINITION
Reproductive Justice	The human right to maintain personal bodily autonomy, not have children, or have children, and parent the children in safe and sustainable communities. Reproductive justice, different from the reproductive rights movements of the 1970s, emerged as a movement because women with low incomes, women of color, women with disabilities and LGBTQ+ people felt marginalized in the reproductive rights movement, which focused primarily on pro-choice versus pro-life debates. Reproductive justice acknowledges intersecting factors such as race and class that impact marginalized groups of women differently, and links reproductive rights with the social, political and economic inequalities that affect a woman's ability to access reproductive health care services. Core components of reproductive justice include equal access to safe abortion, affordable contraceptives and comprehensive sex education, as well as freedom from sexual violence.
Sepsis	A clinical syndrome of life-threatening organ dysfunction caused by the body's inappropriate response to infection.
Severe Maternal Morbidity	Unexpected outcomes of labor and delivery that result in significant short- or long-term consequences to a woman's health. It is an important risk factor for maternal death, as is premature birth.
Social Determinants of Health	The many different social, economic, historic, and environmental factors which shape health. Social determinants are the characteristics of where we live, work, play, shop, worship, study, seek help, etc. that impact health.
Stakeholders	Individuals, institutions, organizations, agencies, etc. that are invested in a situation. First among primary stakeholders are those who have been historically most harmed by the problem and would benefit most by an equitable resolution. In the case of Nurture NJ, other stakeholders include community organizations, government agencies and institutions (federal, and state, and local), philanthropic organizations, Departments of Health and Transportation, private and public agencies and institutions (hospitals, clinics, universities, etc.), and businesses.
Substantive Racism	Laws and overt practices that openly treat people as inferior based on race. The history of race-based immigration laws, laws that disregarded the sovereignty of American Indian tribes and the cultures of Indigenous Peoples, two and a half centuries of laws that connected enslavement with Black people, Jim Crow/Black Code laws, and the doctrine of "separate but equal" are examples from U. S. history.
Transactional Change	An issue-based approach that helps individuals negotiate existing structures. These solutions transact with institutions to get a short- term gain for communities but leave the existing structure in place. They involve routine solutions using skills and experience readily available.
Transformative change	Initiatives that cross multiple institutions and shift efforts toward proactive solutions. These solutions alter the way institutions operate, thereby shifting cultural values and political will to create equity. The approach requires changes in values, beliefs and work. It is solved by the people with the problem and requires change in numerous places, usually across organizational boundaries

TERM	DEFINITION
Value-based Care	Value-based healthcare is a healthcare delivery model in which providers, including hospitals and physicians, are paid based on patient health outcomes. Value-based care revolves around how well healthcare providers can improve their quality of care based on certain metrics, such as reducing hospital readmissions, improving preventative care, and using particular kinds of certified health technology. Under value-based care agreements, providers are rewarded for helping patients improve their health, reduce the effects and incidence of chronic disease, and live healthier lives in an evidence-based way. Value-based care differs from a fee-for-service or capitated approach, in which providers are paid based on the amount of healthcare services they deliver. The "value" in value-based healthcare is derived from measuring health outcomes against the cost of delivering the outcomes.

Appendix II

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Appendix III

Brooks Equity/Inequity Typology (BET)

The **Brooks Equity/Inequity Typology** (**BET**) is a cross-disciplinary tool for research and evaluation, program, and policy formation. It aids in identifying, naming, measuring, interpreting, resolving and planning that concern the support of equity and the elimination of inequity.

This typology is a kind of map. It shows where inequities—like racism and other -isms—have been known to operate historically within society, sometimes quite hidden. Though primarily developed from cross-disciplinary English-language academic sources concerning the long history of structured racial inequities in the United States, this typology has usefulness in work on virtually all types of societal inequities. This includes but is not limited to inequities based on: gender, class, age, sexual orientation, ability, etc., and the intersections/interactions of these kinds of larger societal forces.

The **BET** has many uses: it can serve as a first-level screening of situations or for deeper-level analyses. The principles and goals that support the **BET** are that people and groups (e.g. racial, gender and class groups, etc.) are to have their humanity valued. They are to be treated with equity, respect, dignity, justice, care and consideration, all of which are consistent with United Nations goals and principles of human rights.

Individuals and groups that have been disadvantaged by societal inequities have the greatest and most immediate investment in removing those inequities, repairing those circumstances, and securing restitution. From their subordinate position, these individuals and groups observe and experience the inequity very differently from those individuals and groups that are in the super-ordinate position. Hence, it is important to know key background characteristics of the persons who are responding to items on the *BET*. This serves to position the observer within some of the various hierarchies of the particular society in which particular inequities exist.

The content of the *BET* is multi-disciplinary and rooted in history. The content derives from three major sources: a) dozens of English language multi-disciplinary and international definitions of racism; b) 500 years of US history concerning the treatment of five different racial populations in the US (Indigenous Americans, African Americans, Latino Americans, Asian Americans, and Indigenous Hawaiians); and c) 33 manifestations/forms of racism (e.g. *institutional racism, dysconscious racism, procedural racism,* etc.) as described across different academic fields: e.g. sociology, law, public health, anthropology, ethnic and women's studies, history, education, psychology and medicine.

Conceptual analyses of material from the above three major sources yielded nine inter-related non-mutually exclusive categories. The core of the **BET**, these nine categories are:

- 1. Power and Authority; 2. Rules; 3. Actions/Emotions; 4. Ideology/Thinking; 5. Systems and Institutions; 6. Environment (Physical Environment and Social Environment);
- 7. Developmental/Lifespan Human Development; 8. Resources and Services; and
- 9. Legacy/Historical Accumulations.

Use of this typology encourages both deep and broad views of equity/inequity. The same nine categories identify both circumstances where inequities may need to be removed/dissolved as well as circumstances where new efforts can build and support more equitable systems, institutions and practices. Additionally, the *BET* can be used to collect either quantitative or qualitative data. A brief sample from only the first of the nine categories follows below:

Concerning the specific circumstance that you are exploring, are there indications of INEQUITIES [racial or other kinds] in any one or more of the following nine areas (I–IX)?

I. POWER and AUTHORITY
For example:
☐ Naming, defining and/or framing problems or issues to be addressed
☐ Assigning importance and/or priority to problems or issues
Proposing solutions
☐ Determining the processes and systems to be used
☐ Making key decisions
☐ Enforcing key decisions
Assuring safety, protection and preservation
 Influencing, accessing, possessing, controlling and/or allocating resources (such as money, materials, staff, services, training, education)

Appendix IV

Author Bios

Vijaya K. Hogan, MPH, DrPH

Dr. Vijaya Hogan is Principal Consultant at VKH Consulting, LLC. Dr. Hogan is a perinatal epidemiologist by training. She has worked in philanthropy (WK Kellogg Foundation), Academia (Professor at University of North Carolina at Chapel Hill, and has worked on local, state, national, global, urban and rural issues in public health. She was a member of the DHHS Secretary's Advisory Committee on Infant Mortality, and currently serves as Adjunct Professor at the University of North Carolina at Chapel Hill. Dr. Hogan is committed to understanding how social environment and historical factors translate into inequitable health outcomes and provides technical support in strategic planning to support and promote equity.

Lisa A. Asare, MPH

Lisa Asare is Assistant Commissioner for Health at the New Jersey Department of Health. She is an accomplished executive public health professional, experienced in conceiving, implementing and managing cross-sector projects that advance health, equity, and build strategic partnerships. With over 20 years of experience, she displays an in-depth knowledge of population health, public health, public policy, and government infrastructures.

Bahby Banks, PhD, MPH

Dr. Bahby Banks is a leadership strategist, diversity consultant and implementation scientist based in Durham, North Carolina. She is the founder and CEO of Pillar Consulting, a program evaluation research firm dedicated to helping non-profit, philanthropic and corporate organizations measure the impact of their initiatives. Dr. Banks's work has spanned the Americas, Africa, Europe, and Australia. This multilingual scholar is also the creator and facilitator of ENVISION Empowerment Experience™, a leadership intensive that helps attendees develop strategies and create roadmaps to achieve their personal and professional goals.

Luz E. Benitez Delgado, MBA, NCC

Luz Benitez Delgado served in various capacities at the W.K. Kellogg Foundation (WKKF) where she served as the Truth, Racial Healing & Transformation (TRHT) program officer, deputy director to the Vice President for Racial Equity and Racial Healing, Community Engagement & Leadership. Most recently Benitez Delgado served as a key advisor to Papa John's in their efforts to adopt racial equity, diversity and inclusion, and has led healing circles as a healing practitioner at the University of Maryland, School of Social Work. She served as a university scholar at the University of Zimbabwe, and studied and worked for the Rural Associations for Progress in Bulawayo, Zimbabwe, consultant for the Fundación Cozumel, Quintana ROO, Cozumel, México; Latin American Immigrant & Refugee Organization, and many other CBO's.

Debra Bingham, DrPH, RN, FAAN

Dr. Debra Bingham has developed and led several state and national quality improvement initiatives that have reduced maternal mortality and morbidity. She is an Associate Professor of Healthcare Quality and Safety at the University of Maryland School of Nursing where she is expanding the utilization of implementation science and improvement science theories, frameworks, models, and QI methods and tools within the Doctor of Nursing Practice curriculum. She is the principal investigator for the Advancing Implementation Science Education (AdvISE) nurse support II funded by the Maryland Commission of Higher Education. Dr. Bingham is a perinatal consultant and the founder and Executive Director of the Institute for Perinatal Quality Improvement (www.perinatalQl.org).

Pauline E. Brooks, PhD

Dr. Pauline Brooks is an independent evaluator/researcher with particular interests in cross-disciplinary and cross-cultural issues, and the elimination of racism and other structured inequities. She is former Manager of Evaluation for a large California-based health foundation and university professor. She has conducted evaluations of small- and large-scale efforts with and within African American, African communities in the U.S., Latinx and Asian American communities, and in Ethiopia, South Africa, Kenya, and Burkina Faso. She trained and served as a Project Director for Evaluation at UCLA's Center for the Study of Evaluation. She has presented at national and international professional conferences.

Jennifer Culhane, MPH, PhD

Dr. Jennifer Culhane's research interests include the interaction of stress, infection and pregnancy outcomes. She has been the principal investigator for multiple research grants from the National Institutes of Health and the Centers for Disease Control and Prevention, examining the causes of preterm birth with specific emphasis on racial/ethnic disparities. Currently, Dr. Culhane is an Associate Research Scientist at Yale School of Medicine, Department of Obstetrics, Gynecology and Reproductive Sciences. In addition to her work at Yale, she is a Research Associate at the Population Studies Center, University of Pennsylvania Department of Sociology. Her research has been widely published in such journals as the American Journal of Obstetrics and Gynecology, the American Journal of Public Health and Pediatric and Perinatal Epidemiology. Before coming to Yale, she was an Associate Professor in the Department of Pediatrics at The University of Pennsylvania School of Medicine.

Monica Lallo, EdD, MPA, MPM

Dr. Monica Lallo is an educator, team strategist and advocate for improving government and nonprofit services to underserved youth and families. Throughout her professional career, she has been committed to bridging the socioeconomic divide that exists in disadvantaged communities. She has been actively involved in government-funded youth improvement initiatives and her work has heightened capacity building efforts for nonprofit organizations, both domestically and internationally. Dr. Lallo received her Doctorate in Education from Immaculata University., her Master's degree in Public Administration from New York University, and Bachelor's degree in Psychology and Criminal Justice from Rutgers University. She taught several courses at Rowan College at Burlington County (RCBC) in the

Human Services Program as a Senior Adjunct Professor. She has been a training consultant for Local Initiatives Support Corporation (LISC), AmeriCorps and keynote speaker at East Stroudsburg University, Sociology and Criminal Justice Departments.

Elizabeth S. Lee, MPA

Elizabeth Lee is a principal and health care group chair at Venn Strategies, based in Washington, D.C. She has dedicated her career to public health, working in a number of senior level policy roles. As a political appointee in the Obama Administration, Elizabeth was the senior policy advisor to the administrator of the Health Resources and Services Administration, where she was responsible for the 340B Drug Pricing Program, HIV/AIDS issues and maternal and child health initiatives. Prior to her work at the Department of Health and Human Services, Mrs. Lee was a legislative aide to Senator Tammy Baldwin and a Winston Health Policy Fellow with Senator Hillary Rodham Clinton. She received her Master's in Public Administration from New York University's Wagner School of Public Service and her Bachelor's degree from Stanford University.

Esther Nieves, MA, MS

Esther Nieves has worked with grassroots, statewide, and national organizations. Her career experience includes leadership positions in city government (Chicago), not-for-profit/non-governmental, and philanthropy. In these roles, she has supported the self-determination and leadership participation of communities in efforts that improve their quality of life, advance inclusion, and bring about social, political, and economic equity.

Her experience includes serving as director of WK Kellogg Foundation's leadership fellowship program (Community Leadership Network) I and as program officer for the community and civic engagement portfolio; national director of American Friends Service Committee's Project Voice/Human Migration and Mobility Initiative; executive director of Erie Neighborhood House (a community-based settlement house), and, program officer at the Field Foundation of Illinois. She was appointed by Chicago's Mayor Washington to be the executive director of the Mayor's Advisory Commission on Latino Affairs. She is currently a consultant, working on projects and campaigns focused on issues and quality of life concerns in immigrant communities, unaccompanied migrant children, affordable housing and balanced community development, indigenous women and leadership development, capacity-building, community mobilizing and civic engagement strategies. She has a profound interest in community-building efforts that link people to each other and their shared aspirations for social, systemic and structural change.

Diane L. Rowley, MD, MPH

Dr. Diane Rowley is Professor Emeritus in the Department of Maternal and Child Health, Gillings School of Global Public Health at the University of North Carolina at Chapel Hill. She is a medical epidemiologist whose research focuses on disparities and inequities in pregnancy and infant health outcomes. She collaborated with others to develop a theoretical approach to research and evaluation of health inequities among African American populations. Dr. Rowley has a broad range of expertise in maternal

and child health, publications on pregnancy and infant health, a track record of funded community-based participatory research, and experience in program evaluation.

Patricia H. Karimi-Taleghani, BA, MA, C.Phil

Patricia Karimi-Taleghani is currently an Independent Consultant (history, culture, ethnography, evaluation and racial equity). Ms. Karimi-Taleghani received her Master's degree in African Studies from UC Santa Barbara and a C. Phil. in African History (concentration on Ethiopian History) at UCLA. As a Fulbright-Hays Research Fellow, Ms. Karimi-Taleghani conducted field research in Ethiopia. She has researched and taught university courses in African, Ethiopian, African American, and Caribbean History. Interested in issues of intersectionality, she has designed and taught African Women's History and Gender Studies courses. Ms. Karimi-Taleghani has worked on racial equity, mental health, and racial disparities evaluation projects in Black and other underserved and immigrant communities of color in Los Angeles. She also conducts historical research and analyses that focus on maternal/child health, mortality and morbidity and breastfeeding equity in marginalized communities. She and Pauline Brooks published, "Human-Centered Evaluation: Building Bridges, Crossing and Breaking Barriers," in Canadian Evaluation Society Grey Literature database. Ms. Karimi-Taleghani published a chapter based on her Ethiopian research on gender-related issues and spirituality in Women and Religion in the World Series.

Shanta Whitaker, PhD, MPH

Inspired by a desire to help the most vulnerable, Dr. Shanta Whitaker left the laboratory bench to pursue a career in public health. She obtained a Master of Public Health from the Johns Hopkins School of Public Health to understand how the social determinants of health affect underserved populations. Currently, Dr. Whitaker is a vice president in the health policy group at Venn Strategies, a boutique government affairs firm in Washington, D.C. In this role, Dr. Whitaker works on advocacy projects focused on a variety of public health and scientific issues. Dr. Whitaker also holds a Bachelor's degree in Biology from Virginia Union University and a PhD in Microbiology from Yale University. She is member of Alpha Kappa Alpha Sorority, Incorporated and the Links, Incorporated

Tiffani D. Williams, BA, BSN, RN, CBG

Tiffani Williams is a Registered Nurse and leader in the Maternal Health department at Acenda Integrated Health. She currently acts as the Program Director for the Nurse-Family Partnership program which has specially trained nurses regularly visit first time moms-to-be starting early in pregnancy and up until their child reaches their second birthday. Tiffani Williams has served mothers in the community for over eleven years as both a Nurse Home Visitor and in the leadership capacity. Tiffani Williams actively seeks out solutions to improve the racial disparities surrounding maternal health and is an active member of Nurse-Family Partnership's Maternal Health Innovations Advisory Committee. She is a Certified Breastfeeding Counselor whose desire is to increase breastfeeding rates amongst the African American community.

Jatesha "Jaye" Madden-Wilson, LPN

Jatesha "Jaye" Madden-Wilson is a Mom, Serial Entrepreneur, Social Impact Speaker and Activist, Maternal Health Advocate and Self-sufficiency Coach. In her career as a Community Health Nurse, she worked to advocated for her patients' needs. However when she became pregnant and was diagnosed with preeclampsia, she had no idea about the statistics of black women experiencing preeclampsia at high rates. These experiences served as a catalyst for the change she wanted to see and be in her community. Jaye created and directs a women-empowerment organization, *Melinated Moms*, to be the advocacy voice of women across the Melinated Spectrum. In the last three years, she has reached over 1,000 women worldwide. She proudly serves on the Nurture NJ strategic planning team with Dr. Vijaya Hogan to improve the birthing outcomes for women of color across New Jersey

Appendix V

Nurture NJ Strategic Plan Suggested Interim Measures

The measures below are suggested ways to track progress toward implementation of the Nurture NJ Strategic Plan. In some cases, it is fairly straight forward to establish completion of a recommendation; in others, suggested measures can track progress toward completion of a recommendation. This list is nowhere near comprehensive – it is intended to be a starting point for a more robust tracking and evaluation plan.

Action Area 1. Build racial equity infrastructure and capacity.

- Declaration of racism as a public health emergency
- Statements from associations representing multiple sectors, including healthcare, private businesses, faith-based organizations, consumer groups, and others
- Establishment of the State Equity Office and fully staffing it
- Percentage of government employees who have undergone an equity capacity assessment
- Percentage of government employees who have undergone an equity training
- Number of state agencies who have undergone an equity assessment and made resultant changes
- Planning completed for a Truth and Reconciliation Healing process in New Jersey

Action Area 2. Support community infrastructures for power-building and consistent engagement in decision-making.

- Number of community forums held to enhance readiness to engage in decision-making processes
- Number of community groups engaged in state advocacy with advising/partnering with state agencies
- Number of state agencies with a stated commitment to community engagement
- Number of state grants and contracts revised to include or increase funds for community engagement
- Development of a template partnership agreement between a state, county and local agency and a community-based group

Action Area 3. Engage multiple sectors to achieve collective impact on health.

- Identification of locations for place-based pilots
- Hiring of a Nurture NJ Coordinator
- Establishment of an innovation center and formalized partnerships with academic, business and faith leaders
- Number of place-based pilots launched
- Number of businesses providing support to Nurture NJ initiatives
- Number of funders providing support to Nurture NJ initiatives

- Number of workplaces that become baby friendly/family friendly
- Number of businesses that conduct racial equity capacity development training

Action Area 4. Shift ideology and mindsets to increase support for transformative action.

- Execution of a statewide communications campaign
- Healthcare and other service providers implementing comprehensive implicit bias training

Action Area 5. Strengthen and expand public policy to support conditions for health in New Jersey

- Percentage of eligible women of child-bearing age that use the EITC
- Percentage of eligible pregnant women who take advantage of paid leave
- Number of employers actively encouraging paid leave

Action Area 6. Generate and more widely disseminate information for improved decision-making.

Number of organizations and individuals accessing/downloading state data

Action Area 7. Change institutional structures to accommodate innovation and transformative action

- Number of state agencies that have a functional equity capacity development structure
- Number of private sector organizations that have a functional equity capacity development structure
- Number of state agencies that have a functional community engagement structure
- Number of private sector organizations that have a functional community engagement structure

Action Area 8. Address the social determinants of health.

- Percentage of women with access to (both statewide and in hotspot/pilot communities):
 - Affordable, safe housing
 - Nutritious food
 - Neighborhood without environmental hazards
 - Quality child care
 - Obstetric provider of her choosing for the duration of pregnancy and postnatal care
 - Postnatal supports
- Number of active planning teams developing place-based pilots

Action Area 9. Improve the quality of care and service delivery to individuals.

Number of Baby-Friendly designated hospitals in New Jersey (at least one hospital in all infant
mortality hotspot areas); alternatively, proportion of Black pregnant individuals delivering in BabyFriendly hospitals; number of hospitals on the path to a Baby-Friendly designation

- Number of hospitals, FQHCs and other care providers with maternal mortality- and morbidity-related quality improvement initiatives that consider the demographic diversity of New Jersey's mothers, including race, ethnicity and socioeconomic status.
- Number of persons who give birth in New Jersey who should be cared for at a birthing hospital or facility that provides the appropriate level of maternal care
- Commitments from New Jersey hospitals to help train, recruit and hire staff from the community, including investments in building the clinical staff to reflect the community through support to medical schools, nursing schools, and community health workers